

NUTRITION CARE FOR LONG-TERM CARE RESIDENTS WITH DEMENTIA IN URBAN
AND RURAL CONTEXTS: AN EVIDENCE BASED PRACTICE EXAMINATION OF THE
ROLE OF CARE AIDES AND REGISTERED DIETITIANS

A Thesis Submitted to the College of
Graduate and Postdoctoral Studies
In Partial Fulfillment of the Requirements
For the Degree of Doctor of Philosophy
In the College of Pharmacy and Nutrition
University of Saskatchewan
Saskatoon

By

ALLISON LEE CAMMER

© Allison Lee Cammer, May, 2018. All rights reserved.

PERMISSION TO USE

In presenting this dissertation in partial fulfillment of the requirements for a postgraduate degree from the University of Saskatchewan, I agree that the Libraries of this University may make it freely available for inspection. I further agree that permission for copying of this dissertation in any manner, in whole or in part, for scholarly purposes may be granted by the professor or professors who supervised my dissertation work or, in their absence, by the Head of the Department or the Dean of the College in which my dissertation work was done. It is understood that any copying or publication or use of this dissertation or parts thereof for financial gain shall not be allowed without my written permission. It is also understood that due recognition shall be given to me and to the University of Saskatchewan in any scholarly use which may be made of any material in my dissertation.

DISCLAIMER

Reference in this dissertation to any specific commercial products, process, or service by trade name, trademark, manufacturer, or otherwise, does not constitute or imply its endorsement, recommendation, or favouring by the University of Saskatchewan. The views and opinions of the author expressed herein do not state or reflect those of the University of Saskatchewan, and shall not be used for advertising or product endorsement purposes.

Requests for permission to copy or make uses of materials in this thesis/dissertation in whole or part should be addressed to:

Assistant Dean, Division of Nutrition
College of Pharmacy and Nutrition
University of Saskatchewan
Saskatoon, Saskatchewan
Canada

OR
Dean
College of Graduate and Postdoctoral Studies
University of Saskatchewan
116 – 110 Science Place
Saskatoon, Saskatchewan, S7N 5C9
Canada

ABSTRACT

This doctoral dissertation contributes to the body of knowledge pertaining to nutrition care for persons with dementia. The aging population adds to the increased risk for and prevalence of dementia globally. Alongside this is a recognition of the need for care strategies for persons with dementia, and preventive strategies to delay onset of dementia or to delay secondary or tertiary comorbidity associated with dementia. Of strong interest is the field of nutrition, in terms of dietary strategies for primary prevention of dementia, for secondary and tertiary prevention of comorbidities, and for medical nutrition therapies to treat those with dementia, across the spectrum of dementing illnesses and degree of severity. Over the course of three related studies, nutrition care for long-term care (LTC) residents was addressed using an evidence-based practice lens.

Study 1 investigated care aides' perception of nutrition care for urban and rural LTC residents with dementia. Key findings included the complexity of operationalizing person centered care into nutrition care activities, the mechanistic focus on feeding, and many organizational factors that direct nutrition care for care aides and residents with dementia. Study 2 examined the role of registered dietitians (RDs) in providing nutrition care for residents with dementia in urban and rural LTC. The key finding in this study was the downstream role of RDs in dementia care. As opposed to a more upstream preventive model of care, RDs were consulted or involved only at late stages or when comorbid decline had occurred, limiting their abilities to use their specialized nutrition knowledge and skills effectively. The 3rd study was an umbrella review of the peer-reviewed body of systematic reviews on nutrition care for residents with dementia in LTC. The major findings of this study include the lack of consistency in terms of nutritional outcomes

considered and intervention tested, as well as a considerable gap in the published literature regarding both care aides and RDs.

Taken together, these studies make a valuable contribution to the growing body of research on nutrition care and dementia. There is a need to continue to work with RDs and care aides in developing and testing interventions that can enhance both the physical health and quality of life for LTC residents with dementia.

ACKNOWLEDGEMENTS

This thesis would not have been possible without the generous support and mentorship from my co-supervisors Dr. Susan Whiting and Dr. Debra Morgan. Their extraordinary intellect is only equaled by their kindness. I would like to acknowledge the guidance and encouragement provided by my advisory committee: Dr. Phyllis Paterson, Dr. Roy Dobson, and Dr. Donna Goodridge. I am fortunate to have had such a competent and inspiring committee.

I am grateful for the financial and training support provided to me by The Alzheimer Society of Canada, Canadian Centre for Health and Safety Founding Chairs Program, CIHR-STIHR Public Health and Agricultural Rural Ecosystem program, Western Regional Training Centre for Health Services, CIHR Institute of Aging, College of Pharmacy and Nutrition, McIntyre Foundation, and Dietitians of Canada.

My knowledge translation committee were instrumental in the research process. Seshni, Janet, and Charlotte: your enthusiasm was outstanding. To the long-term care dietitian and care aide participants: your dedication and caring is inspiring. The wise counsel and radical optimism of Dr. Norma Stewart proved invaluable, and I am grateful to the Alzheimer Society of Saskatchewan, RaDAR research team, and Rural and Remote Memory Clinic colleagues for their unending support.

Finally, I owe a debt of gratitude to my friends and family. Friends (you know who you are!), words cannot express how much I treasure you. Thank you to Josh and Gracie for reminding me why it is important to pursue dreams, and to Jess for her ever-present backing, her sardonic wit, and her confidence in me when I couldn't find my own. Finally, without Neil and Lou's unconditional love and encouragement I would never have been brave enough to attempt this.

TABLE OF CONTENTS

1.0 GENERAL INTRODUCTION	1
2.0 LITERATURE REVIEW	7
2.1 Dementia	7
2.1.1 Impact of Dementia	9
2.1.2 Trajectory of Dementia Care	10
2.1.3 Nutrition and Risk of Developing Dementia	11
2.1.4 Nutrition and Dementia Care	14
2.2 Long-term Care and Dementia	21
2.2.1 Rurality and Long-term Care	24
2.3 Nutrition Care for Residents with Dementia in Long-term Care	27
2.4 Long-term Care Staff and Dementia	35
2.4.1 Care Aides and Nurses	35
2.4.2 Registered Dietitians	39
2.5 Evidence-based Practice	42
2.6 Integrated Knowledge Translation and Exchange Research	45
2.7 Qualitative Methodologies	47
3.0 METHODS	49
3.1 Knowledge Translation and Exchange Committee	49
3.2 Care Aide Study	50
3.3 Registered Dietitian Study	52
3.4 Umbrella Review Study	54
4.0 NUTRITIONAL CARE FOR RESIDENTS WITH DEMENTIA IN RURAL AND URBAN LONG-TERM CARE HOMES: PERSPECTIVES OF CARE AIDES	56
4.1 Background	56
4.2 Methods	59
4.2.1 Setting and Participants	59
4.2.2 Data Generation	59
4.2.3 Data Analysis	61

4.3 Findings	61
4.3.1 Thematic Categories	62
4.3.1.1 Experiential Learning	63
4.3.1.2 Balancing Resident Care Needs	64
4.3.1.3 Operational Demands	65
4.3.1.4 Coping Strategies	66
4.3.1.5 Operationalizing Person Centered Care	68
4.3.1.6 Perception of Nutrition Care	69
4.3.2 Case Scenario	71
4.3.3 Impact of Rurality	74
4.4 Discussion	75
4.5 Limitations	80
4.6 Conclusion	80
5.0 THE DOWNSTREAM ROLE OF REGISTERED DIETITIANS PROVIDING NUTRITION CARE FOR RESIDENTS WITH DEMENTIA IN THE LONG-TERM CARE SETTING	81
5.1 Introduction	81
5.2 Research Question	83
5.3 Methods	83
5.3.1 Setting and Participants	84
5.3.2 Data Generation	84
5.3.3 Data Analysis	85
5.4 Findings	86
5.4.1 The Grounded Theory: The Downstream Role of Registered Dietitians in Dementia Care	86
5.4.2 Theoretical Categories	87
5.4.2.1 Resources	89
5.4.2.2 Siloing	93
5.4.2.3 Relationships	98
5.4.2.4 Practice Expertise	101

5.4.3 Impact of Rurality	104
5.5 Discussion	106
5.6 Limitations	112
5.7 Implications for Practice	112
6.0 UMBRELLA REVIEW OF NUTRITION CARE FOR RESIDENTS WITH DEMENTIA IN LONG-TERM CARE HOMES	114
6.1 Introduction	114
6.2 Research Objective	115
6.3 Methods	116
6.4 Results	119
6.5 Discussion	134
6.6 Limitations	138
7.0 DISCUSSION	139
7.1 Nutrition Care for Residents with Dementia in Rural and Urban Long-term Care Homes: Perspectives of Care Aides	140
7.2 The Downstream Role of Registered Dietitians Providing Nutrition Care for Residents with Dementia in the Long-term Care Setting	142
7.3 Nutrition care for Residents with Dementia in Long-term Care: An Umbrella Review of Current Evidence	143
7.4 Relationship between Studies and Overall Conclusions	143
7.5 General Limitations	147
7.6 Implications for Practice and Future Research	148
8.0 REFERENCES	150

LIST OF TABLES

Table 2.1	Risk factors and protective factors for development of dementia	14
Table 2.2	Dementia sub-types, BPSD, and potential nutritional implications	16
Table 2.3	Sample nutrition care practices to support LTC residents with dementia	31
Table 4.1	Demographic characteristics of care aide participants	62
Table 4.2	Thematic categories – care aide study	62
Table 6.1	Examination of review studies included in umbrella review	120
Table 6.2	Examination of recommendations made specifically to LTC staff, care aides, and dietitians	131

LIST OF FIGURES

Figure 2.1	Trajectory of dementia care	11
Figure 2.2	Nutrition-related difficulties with progression of dementia	19
Figure 5.1	The downstream role of the dietitian in dementia care	88
Figure 6.1	PRISMA flow diagram of umbrella review	118

LIST OF APPENDICES

Appendix 1	Consent form for care aide participants	167
Appendix 2	Consent form for registered dietitian participants	171
Appendix 3	Sample MESH terms and keywords	175

Chapter 1.0: General Introduction

Dementia is now recognized as a worldwide public health priority and the number of people with dementia is projected to double to 65.7 million by 2030 (WHO, 2012). The current population demographics and increasing prevalence of dementia have a significant effect on need for formal care. Dementia is the top chronic condition necessitating relocation to long-term care (LTC), and residents with dementia require more direct-care time compared to those without dementia (Prince et al., 2013).

Nutrition care is central to resident health, and there is growing evidence demonstrating the critical importance of nutrition care for residents with dementia living in LTC in terms of physical health and quality of life (Keller, 2017). While nutrition intervention may not reduce dementia mortality, it can help to slow the progression of dementing illnesses and can increase quality of life (Prince et al., 2014).

Despite the risks associated with malnutrition, nutrition care is not regulated in Canadian LTC facilities; standards and practices can vary between and within facilities or even within care provider category. Within LTC, the majority of resident care is provided by aides who have limited training in both nutrition and dementia and rely on task-specific nutrition care (Pelletier, 2005). Rural LTC facilities may be further disadvantaged due to limited access to specialist care including dietitians to aid in resident-centered diet, intake, and feeding guidance. Residents with dementia face problems with oral intake and nutritional status due not only to the physical disease progression but also due to care, as staff in LTC report difficulty in food provision and feeding residents with dementia (Pasman et al., 2002). The role for dietitians in LTC is increasing (Wassink et al. 2010), however, current practice recommendations for nutrition care in LTC do not address dementia (DC, 2013). Dementia is not addressed in the widely used

Dietitians of Canada's 'Best Practices for Nutrition, Food Service, and Dining in Long Term Care Homes' (DC 2013).

Evidence-based practice (EBP) is recognized as a fundamental to care provision, and has gained acceptance in LTC (Gitlin et al., 2015). Sackett's model of EBP includes three key components: research evidence, clinical expertise, and patient values and preferences (Sackett et al., 2000). A useful analogy is to envision evidence-based practice as the seat of a stool with each of the components representing a leg of the stool; stability and strength of the entire stool is compromised when any of the legs is lacking. Within the context of LTC, EBP can be viewed as a successful integration of person-centered care (patient values and preferences), executed by competent skilled staff (clinical expertise) whose work is governed by best practice standards and policies (research evidence). With this in mind, examination of nutrition care for residents with dementia in rural LTC using a lens of EBP is timely, with opportunity to significantly improve dietetic practice and nutrition care.

Despite the growing interest in nutrition and dementia, there is very little research available regarding the role of care aides in nutrition care of LTC residents with dementia or the role of registered dietitians (RDs) in nutrition care of LTC residents with dementia. The purpose of this doctoral research is to investigate these roles from the perspectives of care aides and RDs themselves, and to determine the current state of the formal body of evidence as it relates to care aides and RDs and nutrition care practices for LTC residents with dementia. The following is a brief description of the three studies that comprise this doctoral research.

Study 1: Nutritional Care for Residents with Dementia in Rural and Urban Long-term Care Homes: Perceptions of Care Aides

Care aides provide the majority of direct care within LTC homes. As such, they are responsible for delivering much of the direct nutritional care, especially mealtime assistance, that a resident with dementia receives. Givens et al. (2009) found that the majority of decisions made by healthcare proxies of persons with dementia were regarding management of eating and drinking problems, not surprising considering the high rate of nutrition-related activities of daily living difficulty among persons with advanced dementia. A study by Mitchell et al. (2009) found that 86% of nursing home residents developed difficulty with feeding. Nutrition care, particularly meal provision, is often routinized and task-focused (Sidenvall, 1999) rather than person-centered and encompassing of best practices for resident care. Examining the principles of nutritional care for persons with dementia from the perspective of care aides is an important step in understanding how to best communicate best practices and translate these into effective nutrition care.

An examination of how care aides conceptualize nutrition care provision can lend insight into the sources and types of evidence that inform nutrition care for residents with dementia. With an understanding of the factors that aides consider when providing nutrition care to residents with dementia, we can better plan policy, train care providers, and educate the public on matters of healthy eating and dementia in LTC. The objective of this study was to examine nutrition care practices for residents with dementia living in urban and rural LTC settings from the perspective of care aides.

Study 2: The Downstream Role of Registered Dietitians Providing Nutrition Care for Residents with Dementia in the Long-term Care Setting

Dietitians are known to be experts in nutrition care. However, little is published on the role of RDs in LTC (Wassink, 2010) and even less is understood about the role of the RD in dementia care. A report by Alzheimer Disease International advocates for dietitian involvement in the complex nutritional care for persons with dementia both at the primary health or diagnostic level and at the LTC level (Prince et al., 2014). The report recognizes dietitians as experts in the field of nutrition and recommends “all people with dementia, and their family carers, should receive dietary advice from a dietitian as a part of post-diagnostic care, updated, as appropriate, as their condition evolves, particularly with the onset of weight loss, aversive feeding behaviours, and need for feeding assistance.” (Prince et al., 2014, p. 5).

To date, only Ontario and British Columbia have provincial LTC standards of care in place that mandate RD care in LTC (BC Community Care and Assisted Living Act, Residential Care Regulations, 2009; ON Ministry of Health and Long-Term care, 2010). BC’s current legislation requires care planning with an RD within 30 days of admission, while ON has a legislated minimum standard of 30 minutes of RD time per resident per month. A 2010 Dietitians of Canada (DC) Ontario LTC Action group document ‘Roles and Responsibilities of the Registered Dietitian (RD) in Ontario LTC Homes’ identifies direct clinical care responsibilities and indirect care responsibilities in ensuring quality nutrition care for all residents of LTC, but notes that the time standard is based only on an approximation of time required to fulfill direct care and specific administrative responsibilities. Direct clinical care includes nutritional assessment and monitoring, development of nutrition care plans, charting, monitoring, and providing nutrition counseling and nutrition education; indirect care responsibilities include participating in care

teams, developing policies/procedures, and providing in-service education to dietary and other staff; administrative responsibilities include menu review, and therapeutic diet policies (DC, 2010). It is noteworthy that dementia is not mentioned within this document; neither is the role of the RD in providing nutrition care for residents with dementia addressed elsewhere in known guidelines or standards.

Wassink's 2010 study of the role of the RD in LTC identified specific tasks germane to RDs in LTC (performing nutritional assessment, ensuring adherence to quality assurance guidelines, participating in resident care conferences, and providing education to staff) but emphasized a broader role as a member of the care team where the RD actively mentors and maintains focus on the purpose of nutrition care (Wassink, 2010). The role of RDs specific to dementia care has not been examined, however.

A Canadian study conducted in 2003 by Keller et al. showed that LTC residents with dementia who received enriched care via increased RD time and menu modification or enhancement had better weight maintenance in comparison to a control group receiving regular care (Keller et al., 2003). Smith and Greenwood emphasize the importance of early intervention to prevent or stymie weight loss and decline, as older adults with dementia are less responsive to interventions aimed at increasing intake (Smith & Greenwood, 2007). Based on this evidence, it is clear that RDs can play a critical role in preventing decline and enhancing care of LTC residents with dementia.

The primary objective of this study is to gain an in-depth understanding of the current role of the RD in providing nutrition care to residents with dementia in urban and rural LTC contexts.

Study 3: Umbrella Review of Nutrition Care for Residents with Dementia in Long-Term Care Homes

Thorough examination of the peer-reviewed, published literature on the best practices regarding nutrition care for persons with dementia living within LTC is a crucial to understanding the state of the evidence that informs practice. By performing a rigorous umbrella review of the literature, examination of the common interventions studied, outcomes measured, and recommendations that inform best practices for nutrition care of residents with dementia can be understood. Examination of what is reported in the literature or recommended in terms of the role for care aides or role for RDs complements the first two studies and adds to the understanding of the current roles as they are experienced by both of these care provider groups.

The objective of this study is to increase understanding of the evidence base specific to nutrition care for LTC residents with dementia through an umbrella review of published systematic review studies.

This doctoral thesis includes a review of the literature, methods used to conduct the specific studies, description of each of three studies that comprise the research, and a general discussion of the research findings as well as how each distinct study relates to one another informs future research and practice. The first study is an examination of the nutrition care for residents with dementia from the perspective of care aides working in rural and urban LTC contexts. The second study is an examination of the role of RDs in nutrition care for residents with dementia from the perspective of RDs practicing in rural and urban LTC contexts. The third study is an umbrella review of the current peer-reviewed systematic review literature related to nutrition care of residents with dementia in LTC, with particular attention to the conclusions or recommendations related specifically to care aides and RDs.

Chapter 2.0: Literature Review

2.1 Dementia

According to the World Health Organization (WHO), dementia is “a syndrome, usually of a chronic or progressive nature, caused by a variety of brain illnesses that affect memory, thinking, behaviour and ability to perform everyday activities” (WHO, 2012). Dementia is an “umbrella” term for a variety of diseases or conditions that cause a similar impairment in cognitive and functional ability. These diseases share the feature that they produce brain-based changes that alter cognition and functional abilities, creating impairment in daily life and are thus collectively known as dementias. The most common form of dementia is dementia due to Alzheimer Disease (AD), accounting for over 60% of dementia prevalence (Alzheimer Society Canada, 2010). The second most common type is vascular dementia followed by Lewy body dementia, and frontotemporal dementia (FTD), all attributable to different underlying neurobiological pathologies (Chiu et al., 2006). Symptoms specific to each are addressed in the discussion of early stage dementia and nutrition that follows shortly.

The ability to accurately identify and diagnose sub-types of dementia is challenging. As more is learned about the neurobiology and pathophysiology of these diseases, diagnoses of sub-types can be expected to improve. At the early stage of illness, the diagnosis of sub-types may enable tailoring of interventions and care that best suits the particular type of dementia. As dementia progresses to the more advanced stages, individuals with dementia typically exhibit a global impairment with limited differentiation and distinction between the various subtypes (Lezak, 2012). Late stage interventions may also be better tailored if the dementia sub-type is known, as the reasons underscoring particular behavior could be better addressed. For example, reasons for food refusal may differ among persons with FTD compared to persons with AD. However, since

admission to long-term care (LTC) often occurs in later stages of the disease when cognitive and functional abilities have declined to a point where full-time assistance and care is needed, policies and care plans in LTC are typically general rather than specific in order to address this global impairment version of dementia.

While there can be a wide variety of symptoms expressed or deficits experienced depending on the sub-type of dementia, a general all-cause diagnostic criteria has been developed by the National Institute on Aging. “Dementia is diagnosed when there are cognitive or behavioral (neuropsychiatric) symptoms that:

1. Interfere with the ability to function at work or at usual activities; and
2. Represent a decline from previous levels of functioning and performing; and
3. Are not explained by delirium or major psychiatric disorder;
4. Cognitive impairment is detected and diagnosed through a combination of (1) history-taking from the patient and a knowledgeable informant and (2) an objective cognitive assessment, either a “bedside” mental status examination or neuropsychological testing.
Neuropsychological testing should be performed when the routine history and bedside mental status examination cannot provide a confident diagnosis.
5. The cognitive or behavioral impairment involves a minimum of two of the following domains:
 - a. Impaired ability to acquire and remember new information—symptoms include: repetitive questions or conversations, misplacing personal belongings, forgetting events or appointments, getting lost on a familiar route.
 - b. Impaired reasoning and handling of complex tasks, poor judgment—symptoms include: poor understanding of safety risks, inability to manage finances, poor decision-making ability, inability to plan complex or sequential activities.
 - c. Impaired visuospatial abilities—symptoms include: inability to recognize faces or common objects or to find objects in direct view despite good acuity, inability to operate simple implements, or orient clothing to the body.

d. Impaired language functions (speaking, reading, writing)—symptoms include: difficulty thinking of common words while speaking, hesitations; speech, spelling, and writing errors.

e. Changes in personality, behavior, or comportment—symptoms include: uncharacteristic mood fluctuations such as agitation, impaired motivation, initiative, apathy, loss of drive, social withdrawal, decreased interest in previous activities, loss of empathy, compulsive or obsessive behaviors, socially unacceptable behaviors.” (McKhann, Knopman, Chertkow, Hyman, Jack Jr, Kawas, Klunk, Koroshetz, Manly, Mayeux, Mohs, Morris, Rossor, Scheltens, Carrillo, Thies, Weintraub, & Phelps, 2011)

2.1.1 Impact of Dementia

Dementia has been chronicled as a public health priority (WHO 2012) and a global epidemic (Prince et al., 2013). Global prevalence of dementia in 2010 was estimated to be 35.56 million people, or 4.7% of the total population (WHO, 2012). This prevalence is projected to increase to 75.62 million people by 2030 and 135.46 million people by 2050 (Prince et al., 2013). The estimated prevalence in North America in 2010 was 6.9% of the population, or 4.38 million people. Within Canada, the estimated prevalence of dementia in 2008 was approximately 1.5% of the total population, or 480,000 people (Alzheimer Society Canada, 2010), and is projected to increase to 2.8% of the total population, or 1,125,000 people by 2038 (Alzheimer Society Canada, 2010). A recent study in SK using provincial administrative health databases (hospitalization, physician service, prescription drugs, and RAI-MDS LTC) calculated the number of persons with dementia in SK at 13,012 in 2012-2013 (Kosteniuk et al., 2015). The researchers noted that underestimation of prevalence could have occurred because they did not have access to RAI-MDS homecare service data and due to physician ability to record only one diagnosis per patient claim, which can be a problem if a patient presents with comorbid conditions (Kosteniuk et al., 2015).

Globally, the financial cost of dementia in 2010 was estimated to be \$604 billion (ADI, 2009).

The US Alzheimer's Association reported that the financial implications to the formal care systems of healthcare for dementia amount to \$214 billion per year (Alzheimer's Association, 2014). As well, the 2013 estimates of unpaid caregiving by family members or other informal support in the US amount to 17.7 billion hours of care per year by over 15 million people (Alzheimer's Association, 2014). In 2010 the estimated economic burden of dementia in Canada in 2008 was \$15 billion per year, and this is expected to increase to \$152 billion by 2038 (Alzheimer Society Canada, 2010).

Dementia is one of the most feared and dreaded conditions (Corner, 2004). A review of public opinion surveys about cognition and aging revealed that more than double the number of people fear loss of cognitive ability (62%) than physical ability (29%), as many as 50% of people surveyed fear development of dementia; 49% were equally afraid of caring for a loved one with dementia as of having dementia themselves (Anderson et al., 2009). The impact of dementia personally, to those with disease and their care partners, and societally is profound.

2.1.2 Trajectory of Dementia Care

As dementia is characterized by incurability and progressive deterioration, a trajectory of general care needs can be predicted. At earlier stages of disease, persons with dementia and their families may require therapeutic care focused on slowing the progression of decline and support in coping with the changes they are experiencing (Alzheimer Society Canada, 2015a). As the disease progresses, more care will be required in order to maintain function. As functional ability declines, more personal care assistance will be required for performance of routine tasks known as activities of daily living (ADL), and at advanced stages of disease, therapeutic care to reduce challenging behaviours is often required in addition to full-time assistance with ADLs

(Alzheimer Society Canada, 2015b). As the dementia progresses, the ability to live independently within the community is compromised and at moderate to later stages of illness, relocation to LTC is common (Alzheimer Society Canada, 2015c). Figure 2.1 depicts a broad overview of the progression of dementia symptoms and typical trajectory from living in the community to living in LTC.

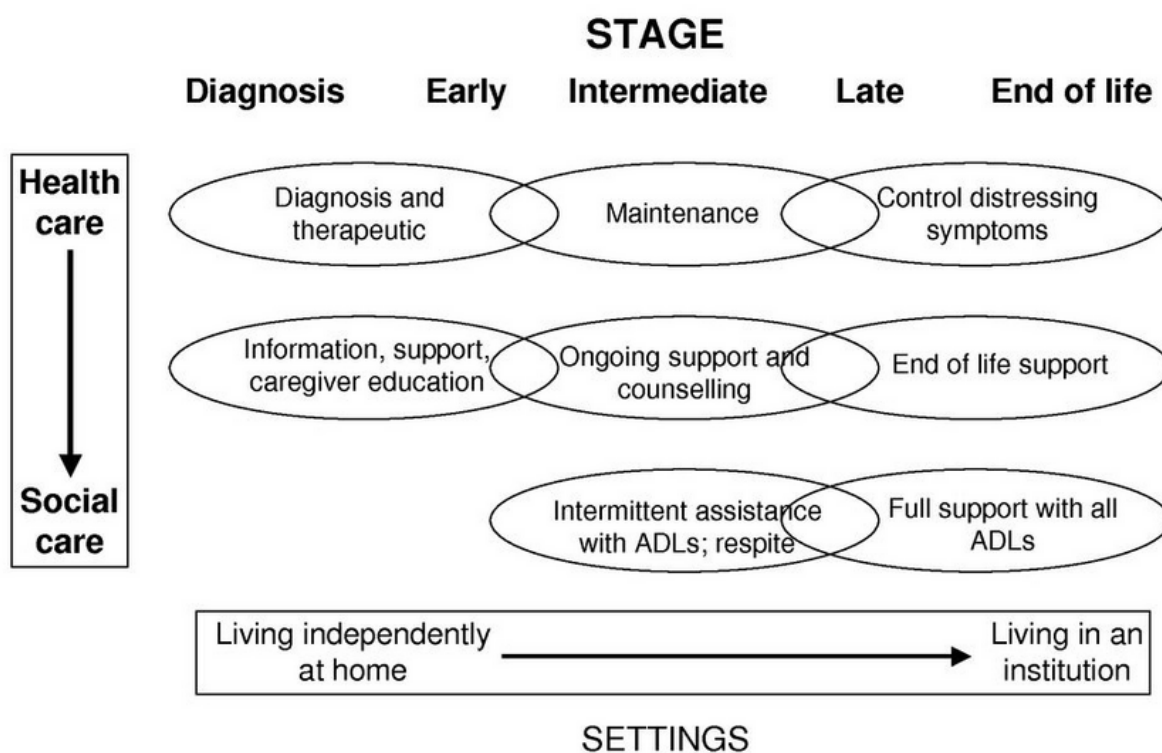


Figure 2.1. Trajectory of Dementia Care; Reproduced with permission from Dementia Care in 9 OECD Countries: A Comparative Analysis, OECD Health Working Papers, 2004.

2.1.3 Nutrition and Risk of Developing Dementia

Morley (2014) has noted that nutrition plays a clear role in cognitive maintenance (Morley, 2014). Deficiencies of particular nutrients such as vitamin B12, folate, niacin, and thiamin have been shown to cause cognitive impairment, and protein energy malnutrition is associated with cognitive deficit (Morley, 2014). There is a growing body of evidence suggesting that reducing the prevalence of nutrition-related chronic conditions such as diabetes mellitus, cardiovascular

disease, hypertension, dyslipidemia, and obesity at mid-life could then reduce the burden of dementia at the population level (Barnes & Yaffe, 2011; Sindi et al., 2015). Research shows that between one-third and one-half of AD cases can be attributed to modifiable risk factors including diet (Kenigsberg et al., 2015; Norton et al., 2014). Barnes and Yaffe (2011) posit that half the cases of AD worldwide are due to seven modifiable risk factors: diabetes mellitus, midlife hypertension, midlife obesity, depression, physical inactivity, smoking, and cognitive inactivity (Barnes & Yaffe, 2011). They project that a 10% risk reduction in these factors could prevent 1 million cases of AD per year and note that these findings would likely be similar for all-cause dementia as well.

The effect of mid-life adiposity on risk of dementia yields mixed findings; some studies have shown an increased risk for late life development of dementia in persons classified as overweight/obese at mid-life, particularly those who had central obesity (Whitmer et al., 2005; Whitmer et al., 2008), yet others have found no association (Albanese et al., 2015). Many trials regarding high-level supplementation of particular nutrients have been undertaken, however a recent systematic review by Shah concluded that supplementation of single nutrients is not recommended at this point, and that obtaining nutrient intake via healthy foods appears more beneficial regarding maintaining cognition (Shah, 2013).

In terms of dietary intake from food, the Mediterranean diet has been researched in terms of its impact on cognitive decline and risk for dementia, and there is evidence that following a Mediterranean diet style of eating is of benefit to cognitive health (Feart et al., 2015). The Mediterranean diet style of eating is characterized by an emphasis on plant based foods such as vegetables and fruits, whole grains, legumes or nuts; use of unsaturated oils such as olive oil instead of saturated fats; limited intake of red meat; moderate intake of poultry, fish, eggs, and

dairy; liberal use of herbs and spices over salt; and moderate intake of wine (Bach-Faig et al. 2011). Recent systematic review concluded that adherence to a Mediterranean diet was associated with lower rates of cognitive decline and possible reduced risk of AD (Lourida et al., 2013; Petersson & Philippou, 2016).

Another diet emphasizing healthy eating patterns, the DASH diet (Dietary Approaches to Stop Hypertension) has shown rates in prevention of cognitive decline similar to the Mediterranean diet (Tangney et al., 2014). The DASH diet is characterized by emphasis on vegetables, fruits, and whole grains; lean meats, poultry, and fish; lower fat dairy choices; nuts, seeds, and legumes; and reduced consumption of sweets and sweetened foods (US Department of Health, 2006). Recent investigation of the MIND diet (Mediterranean-DASH Intervention for Neurodegenerative Delay), developed as an amalgamation of the Mediterranean diet and the DASH diet with emphasis on healthy eating known to be associated with positive brain health, shows promise in slowing cognitive decline and delaying onset of AD (Morris et al., 2015; Morris et al., 2015b).

The relationship of nutrition and risk of developing dementia is an area of growing research. Because there is no known cure, there is much interest in preventing dementia, particularly through nutrition and nutrition-related health strategies. The commonly accepted non-modifiable risk factors, modifiable risk factors, and protective factors are summarized in Table 2.1.

Table 2.1: Risk factors and protective factors for development of dementia. Adapted from Etgen, 2015

Non-Modifiable Risk Factors	Modifiable Risk Factors	Protective Factors
Age Familial and genetic risk factors Family History of Memory complaint	Hypertension Hyperlipidemia Obesity Smoking Diabetes Mellitus Cardiac Disease Chronic Kidney Disease Depression	Mediterranean-style diet Vegetable/Fruit Consumption Physical Activity Light Alcohol Consumption Cognitive and Social Activity

2.1.4 Nutrition and Dementia Care

The goals of nutrition care in the early to moderate stages of dementia are largely focused on preventing physical and cognitive decline, preserving function and ability, and maintaining quality of life for the person with dementia and their care-partners. Until the late stages of dementia, the dementia subtype influences the types of cognitive and behavior changes experienced or symptoms expressed, and these in turn predispose associated nutritional risks.

The early to moderate stage behavioural and psychological symptoms of dementia (BPSD) exhibited in typical AD can be profoundly different from those exhibited in a Lewy body dementia, for example. Typically, AD presents with more memory impairments (Chiu et al., 2006; McKeith & Cummings, 2005), vascular dementia presents with more depression and apathy (Caputo et al., 2008a; Sultzer et al., 1993b), Lewy body dementia presents with more hallucinations, fluctuating cognition or alertness, and sleep disturbances (Chiu et al., 2006; O'Brien, 2003), while FTD presents with hyperorality, disinhibition, and poor judgment or impulsivity (Ahmed et al., 2014; Chare et al., 2014; Chi et al., 2014). Table 2 describes the common BPSD associated with the 4 major subtypes of dementia and the potential nutritional implications associated with those symptoms.

Table 2.2 lists commonly experienced symptoms and their potential associated nutritional implications. However, it is important to note that at the individual level these symptoms could be expressed in many different ways, and individual personality traits, the environment/context, and available informal care supports could create a wide variation in the actual effect experienced. Nutrition-related issues are frequently not identified at the early and middle stages of dementia, which can lead to increased morbidity (Brook, 2014). The characteristic outcome of the nutritional implications for all types of dementia is an increased risk for malnutrition whether it be due to the wrong types of nutrients consumed, reduced ability to procure and prepare foods, reduced ability to eat, overeating, or undereating. The European Society for Parenteral and Enteral Nutrition (ESPEN) guidelines on nutrition in dementia advocate screening for malnutrition as well as close monitoring of nutritional health for persons with dementia (Volkert et al., 2015). Malnutrition due to dementia, if not mitigated, increases decline, severity of symptoms, and deterioration.

Table 2.2: Dementia Subtypes, BPSD, and Potential Nutritional Implications

Dementia Subtype	Behavioural and Psychological Symptoms of Dementia (BPSD)	Potential Nutritional Implications	References
Alzheimer Disease	<p>Memory loss and cognitive impairments</p> <p>Attention difficulties</p> <p>Decreased olfactory sense and impaired odour detection</p> <p>Repetitive actions such as wandering, pacing</p> <p>Irritability, agitation</p> <p>Decreased oral health</p> <p>Loss of appetite</p> <p>Dyspraxia</p>	<p>Forgetting to eat/drink, perform oral care</p> <p>Reduced ability to procure/prepare food, eat, perform oral care</p> <p>Inability to complete food preparation, sit through meals</p> <p>Reduced enjoyment of food, decreased appetite, inability to smell spoiled or unsafe food</p> <p>Increased energy requirements</p> <p>Increased challenge to eating, reduced enjoyment of mealtimes</p> <p>Increased challenge to eating, particularly mastication</p> <p>Decreased intake, reduced enjoyment of foods</p> <p>Difficulty organizing movements in order to cook or eat, such as use of utensils</p>	<p>(Aliani, Udenigwe, Girgih, Pownall, Bugera, & Eskin, 2013; Gillette-Guyonnet, Abellan Van Kan, Alix, Andrieu, & et al., 2007; Greenwood, Tam, Chan, Young, Binns, & van Reekum, 2005; Lezak, 2012; McKeith & Cummings, 2005; Morris & Volicer, 2001; Volicer, Seltzer, Rheaume, Karner, Glennon, Riley, & Crino, 1989; Weijenberg, R. A., Scherder, E. J., & Lobbezoo, F., 2011; Weijenberg, R. A. F., Scherder, E. J. A., & Lobbezoo, F., 2011)</p>
Vascular Dementia	<p>Affective disturbances, agitation</p> <p>Apathy, Low motivation, depressive symptoms</p> <p>Motor difficulties</p> <p>Paranoia and/or delusions</p>	<p>Decreased ability to procure/prepare food and eat</p> <p>Reduced appetite, less interest in and enjoyment of food and eating</p> <p>Difficulty preparing food and eating</p> <p>Challenges in eating (for example, belief that food is unsafe or poisoned)</p>	<p>(Caputo, Monastero, Mariani, Santucci, Mangialasche, Camarda, Senin, & Mecocci, 2008b; Chiu, M. J. et al., 2006; Finkel, 2003; McKeith & Cummings, 2005; O'Brien, J., 2003; Sultzer, Levin, Mahler, High, & Cummings, 1993a)</p>

	Diurnal rhythm disturbances, sleep difficulties	Disrupted meal routine and cues to eat	
	Emotional lability, irritability	Reduced pleasure in eating and social aspect of meals	
Lewy Body Dementia	Fluctuating cognition and alertness	Difficulty completing tasks related to food preparation and eating	(Armstrong, 2015; Chiu, M. J. et al., 2006; Finkel, 2003; McKeith & Cummings, 2005; Shinagawa, Adachi, Toyota, Mori, Matsumoto, Fukuhara, & Ikeda, 2009)
	Sleep disturbances	Disrupted meal routines, falling asleep during meals, nighttime eating	
	Issues with judgment	Challenges determining appropriate portion sizes, assessing when full, decreased enjoyment of social meals	
	Decreased concentration, attention, and visual or auditory hallucinations	Difficulties completing tasks related to procurement/preparation of foods, and increased challenges during eating	
	Physical function difficulties	Challenges to eating and swallowing	
Frontotemporal Dementia	Hyperorality and hyperphagia	Increased risk of compulsive eating, overfilling mouth, consumption of inedible objects	(Ahmed et al., 2014; Chare et al., 2014; Chi et al., 2014; Chiu, M. J. et al., 2006; Finkel, 2003; McKeith & Cummings, 2005; Piguet, Petersén, Yin Ka Lam, Gabery, Murphy, Hodges, & Halliday, 2011; Woolley, Khan, Natesan, Karydas, Dallman, Havel, Miller, & Rankin, 2014)
	Eating disturbances such as binge eating, perseverated eating, overeating	Increased risk for overconsumption/weight gain, overconsumption of some nutrients, inadequacy of others, excessive intake of less healthy foods, alcohol problems	
	Change in taste preference to predominantly sweet flavor	Increased risk of insufficient protein intake	
	Disinhibition and socially inappropriate behavior, poor judgement and impulsivity	Decreased enjoyment of meals, decreased social aspects of eating	
	Difficulty with motor coordination, rigidity	Decreased ability to prepare food, eat	

In the later stages of dementia, there is a blurring of symptoms experienced across the sub-types resulting in a global impairment, as described in section 2.1. At the later stages of dementia, the nutrition care goals are focused primarily on preventing rapid decline and deterioration, preventing malnutrition or the complications of malnutrition, and preserving quality of life. It is estimated that in the advanced stages of dementia as many as 85% of people will experience eating problems (Mitchell et al., 2009). A study of Dutch LTC residents found that those with dementia were 1.5 times more likely to experience malnutrition than residents without dementia, and care dependency was significantly higher among residents with dementia who were rated as malnourished compared to residents with dementia who were not malnourished (Meijers et al., 2014). Eating difficulties for persons with dementia are attributable to apraxia which decreases the mechanical ability to feed oneself, distracting behaviours which limit focus and concentration on the task of eating, prolonged or uncoordinated swallow which increases the time and effort needed to eat, and dysphagia which can cause aspiration (Hanson et al., 2013). Figure 2.2 shows the nutrition-related difficulties that accompany the progression of dementia, culminating in eating difficulties and dysphagia.

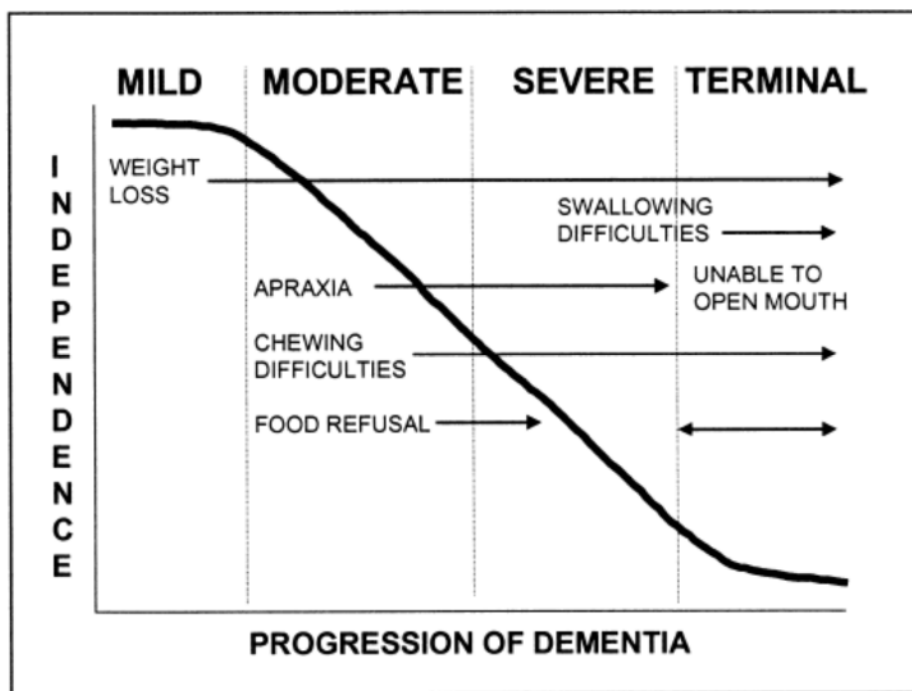


Figure 2.2: Nutrition-related difficulties with progression of dementia. Reproduced with permission from Morris and Volicer, 2001.

Difficulty with eating and dysphagia have been found to be significant causes of malnutrition in later stage dementia (Smith, 2011). Percutaneous endoscopic gastronomy (PEG) is a medical procedure where a tube is endoscopically placed in the stomach via the abdominal wall. Enteral nutrition via nutrients suspended in fluid formula are delivered to the gut through the tube either by syringe, gravity feed with a sterile bag, or with a pump. PEGs require care before and after feeding to flush and clean the tubes, and the PEG stoma requires thorough attention and care to maintain the skin. Though PEG can be used for feeding when oral routes are unavailable, use of PEG tube feeding is largely not recommended as the optimal clinical strategy to address dysphagia for LTC residents, particularly those with dementia (Aparanji & Dharmarajan, 2010; Kim, 2001). A US study of LTC residents with advanced dementia found that 1 in 5 residents who had a feeding tube placement were hospitalized for tube-related complications within the year (Kuo et al., 2009). Placement of PEGs may pose a significant risk to frail residents with

dementia, they may become confused or agitated by feeding tubes and try to pull them out, evidence does not support significant improvements in nutritional health of residents with dementia due to enteral feeding, and enteral feeding does not eliminate risk for aspiration in frail older adults (Aparanji & Dharmarajan, 2010; Harwood, 2014; Ribeiro & Carvalho, 2015). Instead, enteral nutrition via PEG is recommended only when an acute, reversible condition is comorbid with dementia and recovery is anticipated (Gove et al., 2010; Parker & Power, 2013; Volkert et al., 2015).

DiBartolo (2006) cautions against use of PEGs and instead recommends careful hand feeding that includes providing small spoonfuls of properly textured foods, trained staff focusing solely on the resident, and using frequent reminders to chew, swallow, and cough between mouthfuls (DiBartolo, 2006). Harwood (2014) adds that careful hand-feeding must be done slowly to ensure full swallow between mouthfuls, with proper positioning, and involvement of the resident via ‘hand-over-hand’ use of utensils (Harwood, 2014). Amella echoes use of supported oral feeding for residents with dementia and adds that an interdisciplinary care approach should be used to troubleshoot and make adaptations that augment oral feeding and intake (Amella, 2004). Oral feeding may also be advantageous to resident quality of life (QoL). Noting that careful hand-feeding may be more time consuming, Amella advocates for this option due to the attention and social interaction it obliges (Amella, 2004).

Typically, the cognitive and functional impairments that characterize a late stage dementia make it unfeasible to live independently, even with the assistance of care-partners. At that point it is usually necessary to relocate to LTC where continual care and assistance with ADLs is provided. The following section will briefly describe the LTC context and dementia, then address nutrition care and advanced dementia within the LTC context.

2.2 Long-term Care (LTC) and Dementia

LTC has generally not been a top priority among health policymakers (WHO, 2003). However, with an aging population, a higher acuity of illness experienced at end of life, and an expectation of high-quality, often costly care provision, LTC is a sector garnering more attention. In Canada, LTC exists under the category ‘residential care facilities’, defined as “facilities with four beds or more that are funded, licensed, or approved by provincial/territorial departments of health or social services” (Statistics Canada, 2011d). The OECD definition gives more detail about the level and type of care provided within LTC, defining LTC as “...places of collective living where care and accommodation is provided as a package by a public agency, non-profit, or private company. ... a range of services for persons who are dependent on help with basic activities of daily living over an extended period of time. Such activities include bathing, dressing, eating, getting in and out of bed or chair, moving around, and using the bathroom, often in combination with rehabilitation and basic medical services” (OECD, 2005). Though referred to by many other names such as nursing home, special care home, home for the aged or elderly, and geriatric institution, LTC is a commonly accepted term within Canada.

Among OECD countries, it is estimated that LTC spending ranges from 0.2% to 3% of gross domestic product (GDP), with variation between countries depending on the proportion of public financing of LTC and the quality of service offered (OECD, 2013). Canada’s average public spending on LTC between 2006 and 2010 was 1.2% of GDP, and that is projected to increase to between 1.9% and 2.5% by 2060 (OECD, 2013). A 2014 CIHI report noted that the Canadian spending on LTC amounted to \$9.8 billion, a significant amount in health spending (CIHI, 2014).

LTC is not included in the legislation that outlines the principles of the Canadian health system, *The Canada Health Act*, and has been noted as a gap that, in effect, allows the government to evade principles of the Act in terms of providing universal coverage, with variation in eligibility criteria, fees, and services covered (Armstrong, 2008). Instead, LTC is mandated at the provincial and territorial level. The variation in the current provincial LTC systems is rooted in the historical evolution of the system within each province and territory (Banerjee, 2007). Within SK, the provincial health authority, formerly the Regional Health Authorities (RHAs), is responsible for the operation of LTC within the province; the province provides financial transfer to the health authority which then determines budgetary allocations to each LTC home. Hirdes (2002) aptly named the complicated, non-standardized system of LTC in Canada a “policy mosaic” and asserted that the lack of a national approach can create inequalities in how people access services, and can place burden on informal care supports such as family caregiving (Hirdes, 2002). He also noted that the lack of standardization precludes comparison across jurisdictions, particularly between provinces (Hirdes, 2002).

LTC in SK falls specifically under the purview of the Continuing Care Branch of the Ministry of Health. The formal policy that governs LTC operations within SK is the ‘Program Guidelines for Special Care Homes’, released in 2013. These guidelines include a section on food and nutrition services that includes nine subsections to address safe, nutritious, supportive, resident-centered nutrition care within each SK LTC home, however, the specific mechanisms and practices through which this care is achieved is defined and evaluated at the region or facility level (Saskatchewan Health, 2013). As of 2010, there are 2,136 LTC homes operating in Canada amounting to 215,313 LTC beds (Statistics Canada, 2011d). Within SK, there are 129 LTC homes totaling 8092 LTC beds (Statistics Canada, 2011d). A 2013 CIHI report noted that

dementia was the second most common health condition listed on Canadian LTC residents' health record with a 60% prevalence, second only to bladder incontinence at 70% (CIHI, 2013). Armstrong et al. (2009) noted that dementia seems to be a prerequisite for relocation to LTC, as placement within LTC has become increasingly difficult (Armstrong, 2009).

A 2010 study by CIHI, 'Caring for Seniors with Alzheimer's Disease and Other Forms of Dementia,' found that of a sample of 30,645 Canadian LTC residents, 57% had a diagnosis of AD or other dementia in their medical record (CIHI, 2010). However, cognitive impairment and functional ability can be better indicators of care burden due to dementia in LTC than the presence of a formal diagnosis on residents' medical records. In this same study, the cognitive performance scale (CPS) of the RAI-MDS 2.0 data was used to determine the proportion of residents with cognitive impairment, with only 8.4% of residents rated as relatively intact, 46.3% with mild/moderate cognitive impairment, and 45.3% with severe cognitive impairment (CIHI, 2010). Eating impairment is one of the five items that make up the CPS that is used to determine level of cognition in the RAI-MDS 2.0. The other domains that make up the CPS include comatose status, making oneself understood, decision-making ability, and short-term memory, and the CPS has been validated against the Mini Mental Status Exam commonly used to assess cognitive impairment and the MDS cognition scale, though of these, the CPS may be the most conservative in identifying cognitive impairment (Gruber-Baldini et al., 2000).

A measure of functional status, the activities of daily living (ADL) self-performance hierarchy, showed that 4.4% of LTC residents were rated as independent, 16.6% as having limited impairment, 38.6% requiring extensive assistance, and 40.4% as dependent (CIHI, 2010). Again, eating is one of the four ADL self-performance hierarchy scale items used to determine functional dependence, among locomotion, toileting, and personal hygiene. The study also found

that among LTC residents diagnosed with dementia, 85% experienced incontinence, 58% exhibited challenging behavior, and 23% exhibited wandering (CIHI, 2010). This study paints a clear picture of the care load within the Canadian LTC context.

The situation in SK's LTC homes appears comparable to the national data. Similar levels of cognitive impairment and functional dependence are seen according to the RAI-MDS 2.0 cognitive and functional status measures (CIHI, 2011). A 2011 study found that 50.4% of SK LTC residents had a diagnosis of dementia. CIHI's 2011 report 'Health Care in Canada' showed that among SK seniors in residential care, 70% were rated as requiring extensive assistance or dependent on the ADL hierarchy, and 65% were assessed with moderate to severe cognitive impairment. A recent study of a representative sample of Canadian prairie province LTC homes, including SK, showed that over 60% of residents had a diagnosis of dementia and almost half of residents displayed aggressive behaviours or resisted care (Estabrooks et al., 2013). This translates into a LTC context where the majority of residents have extensive care needs. In sum, 'as we look to the future for [LTC] in Canada, the path ahead appears to lead to a more clinically complex population with substantially greater needs for care' (Hirdes et al., 2011).

2.2.1 Rurality and Long-term Care

Leach and Joseph (2011) argue that the context of rurality plays a role in how LTC work is provided and experienced (Leach & Joseph, 2011). While there is a great diversity contained within the term 'rural', ranging from towns with populations less than 10,000 to remote fly-in communities, there are several defining characteristics associated with rurality. According to the 2011 census, rural communities account for approximately 20% of Canadian population, with rural location defined as living outside centres with a population over 1,000 and outside areas with 400 persons per square kilometer (Statistics Canada, 2011a). While the ratio of rural to

urban population in Canada has decreased significantly over time, the rate of decrease has slowed since 1970, and there is still a substantial amount of the Canadian population represented in rural areas (Statistics Canada, 2011c). In SK, the proportion of the population living in rural areas is far more than the national average, at 33% rural and 67% urban (Statistics Canada, 2011b), making attention to rural LTC issues even more important.

The changing demographics of Canadian rural areas include an aging population paired with out-migration of younger people, which combine to impact rural LTC by creating an increased need for LTC while limiting the population available and able to work in LTC (Skinner & Rosenberg, 2006). Rural LTC homes have access to fewer resources compared with urban LTC homes, including information technology, infrastructure, pool of personnel for recruitment/retention, and support from specialized healthcare providers (Leach & Joseph, 2011; Skinner & Rosenberg, 2006). Consequently, rural LTC staff often adapt to inaccessibility of resources by finding ways of coping rather than seeking consultation or relying on support (Leach & Joseph, 2011).

Factoring into this is the difficulty of recruiting and retaining specialist and allied healthcare professionals in rural areas (Buykx et al., 2010). This can lead to vacancies in positions and gaps in the already limited service provided, compounding the disinclination of LTC staff to rely on specialist support. The limited staffing and resultant reduced capacity within rural LTC has been proposed as a factor in the lowered threshold for hospital admission among residents with dementia at end of life (Gessert et al., 2006).

Social support and community cohesiveness are seen to be strengths of rurality and are recognized as key sources of support for aging in rural contexts (Chapman, 2008; Cohen & Bulanda, 2015). However, it has been noted that in some rural areas limited community support available for aging in place or lack of an available informal care network may force some older

adults into LTC earlier than necessary (Cloutier-Fisher & Joseph, 2000). Coburn (2002) reported that a lack of community-based care and availability formal support in rural areas may drive the increased relocation to LTC among rural seniors (Coburn, 2002). Cohen and Bulanda investigated the relationship between social support, rural/urban location, and LTC admission and found that there were no significant differences in rates of nursing home placement based on rurality, and the social support factors were the same whether rural or urban (Cohen & Bulanda, 2015). These authors note that they did not account for quality of social relationships, nor did they measure use of other supportive care services, both of which may be important factors to consider.

Findings from a US study of rurality and LTC quality found that there was a difference in care between urban and rural areas, and this difference, particularly in more geographically isolated LTC homes, was associated with better quality in the rural LTC homes (Phillips et al., 2004). The authors posited that this difference could be in part because rural LTC homes themselves may be positioned within a greater community support network than urban LTC homes. However, quality of care was found to be poorer in rural LTC homes compared to urban LTC homes in a more recent US study (Kang et al., 2011). They used pain and hospitalization as outcomes measures, which may be highly sensitive to reduced availability of specialist care or staff training and support, both features that are lower in rural LTC homes. Thus, rurality in and of itself may not be an independent determinant of LTC quality and should instead be examined amongst the many contextual factors that contribute to quality of care in LTC.

As mentioned, continuity of care in rural LTC can be challenged by poor retention of specialist and allied healthcare providers. Recruitment and retention of qualified healthcare professionals to rural and remote practice locations has long been a challenge. A study in rural Australia found

that among allied healthcare professionals working in rural Australia, the most valued trait of rural practice was a high level of autonomy, while limited professional development opportunities was ranked lowest (Gallego et al., 2015). A qualitative investigation of retention factors among rural allied healthcare professionals found the broad variety and level of authority in rural practice helped retention while the limits to career development and lack of professional development and education in the rural settings hindered retention (Keane et al., 2012). A Canadian study echoed these findings that allied professionals cited variety of work as a reason for working in rural or remote practice, adding that individual personal characteristics such as growing up in a rural location or completing training in a rural site helped in retention of rural allied providers (Manahan et al., 2009). A review of successful retention initiatives for rural healthcare providers found that developing connections among professionals via mentorship programs and enhancing access to continuing professional development and training conference opportunities were among the successful strategies to enhance retention (Buykx et al., 2010).

2.3 Nutrition Care for Residents with Dementia in LTC

Providing for good quality of life (QoL) is recognized as the central purpose of LTC (Terada et al., 2013). Fittingly, the common goals of nutrition care in LTC are prevention of malnutrition and enhancement of resident QoL. As simple as such a statement sounds, nutrition care for LTC residents with dementia is seldom simple or straightforward in practice. Best care practices for LTC residents with dementia are based on the philosophy of person-centered care (Harwood, 2014), originating with the work of Kitwood in the early 1990s (Kitwood & Bredin, 1992). McLean (2007) studied care provided under a biomedical and instrumental approach where persons with dementia were not perceived as having agency and their behaviours were seen as disturbances to be controlled either physically or pharmacologically, and contrasted this with

care provided under a person-centered approach where people with dementia were viewed as individuals with agency and their challenging behaviour was viewed as an attempt at communicating (McLean, 2007).

The precise definition of person-centered care (PCC) in dementia can be difficult to articulate (Brooker, 2003). Building on the work of Kitwood, Brooker (2003) developed a model of person-centered care for persons with dementia comprised of four elements that, combined, comprise the philosophy of person-centered care. These elements, which intentionally spell VIPS, to associate with the acronym for ‘very important persons’, are: 1. Valuing people with dementia and those who care for them (V), 2. Treating people as individuals (I), 3. Looking at the world from the perspective of the person with dementia (P), 4. A positive social environment in which the person living with dementia can experience relative wellbeing (S) (Brooker, 2003). Brooker’s VIPS framework asserts that persons with dementia are valuable regardless of cognitive abilities, are unique and require a tailored approach to care, have perspectives and worldviews that should be respected, and require a socially supportive environment (Brooker, 2007). The Alzheimer Society of Canada endorses person-centered care as the cornerstone of care provision for people with dementia, emphasizing personal ability over loss in function, and focusing on dignity, respect and participation in daily activities (Alzheimer Society Canada, 2011).

Smele and Seeley (2013) note that a PCC philosophy is not without tension when meshed onto the hierarchical institutional culture of LTC, and that the individualized care integral to person centered care is not always attainable in light of staffing ratios and routinized care patterns, but affirm that person-centered care is a positive move toward improved care in LTC (Smele, 2013). A review of PCC for people with severe AD by Edvardsson et al. (2008) concluded that despite a

scarcity of evidence showing clinically valid QoL improvements directly attributable to person-centered care, it should still frame care because person-centered care is respectful, promotes ethical care values, and involves few known or potential risks. (Edvardsson et al., 2008). Reimer and Keller (2009) report that PCC at mealtimes are beneficial to nutritional outcomes in LTC residents (Reimer & Keller, 2009) and Leydon and Dahl (2008) advocate for PCC policies and practices to reduce malnutrition within LTC (Leydon & Dahl, 2008).

Reimer and Keller's model of person-centered mealtimes for LTC includes four elements: promoting social interaction, providing choices and preferences, supporting independence, and showing respect (Reimer & Keller, 2009). They contend that attending to the mealtime environment and experiences of residents during mealtimes is essential to preventing malnutrition in LTC, and assert that person-centered mealtimes are key to facilitating this (Reimer & Keller, 2009). Similarly, research from the UK found that PCC is an overarching theme that unites all other aspects of nutrition care for LTC residents with dementia (Murphy et al., 2017).

Currently, a standard definition and criteria has not been adopted to define malnutrition in LTC residents (Bell et al., 2013). Bell et al. (2015) estimated that 20% of LTC residents exhibit malnutrition, but note that the prevalence varied widely among studies, from 1.5% to 65% (Bell et al., 2015). Weight loss is often used as a proxy measure of malnutrition within LTC, or as an indicator to signal that the resident is at risk of malnutrition. A systematic review by Bell et al. (2013) of measures of nutritional compromise in LTC concluded that weight loss remains the most objective and consistent measure of malnutrition in the LTC setting (Bell et al., 2013). Cognitive impairment and dementia have been found to be significantly associated with an increased risk of weight loss and malnutrition among LTC residents (Bell et al., 2015; Salva et

al., 2009; Volicer et al., 2013) and a study of 2114 LTC residents in Finland found that residents were more than twice as likely to be rated as at risk of malnutrition if they had a diagnosis of dementia (Suominen et al., 2005). A systematic review of factors associated with weight loss among LTC residents concluded that dementia was associated with increased risk of malnutrition (Tamura et al., 2013).

The aims of nutrition care for LTC residents with dementia can then be said to be preserving QoL and preventing weight loss and malnutrition under the auspices of PCC philosophy. Typically, nutrition care recommendations to support LTC residents with dementia focus on enhancing intake in order to prevent weight loss, and the connection to QoL and PCC is not made explicit. Many strategies related to food modification, personnel, and adaptation of the LTC home environment have been investigated to achieve these aims, and are described in Table 2.3, with a focus on those that are suitable to the Canadian LTC context.

Table 2.3: Sample Nutrition Care Practices to Support LTC residents with Dementia

Author and Location	Type of Study	Nutritional Recommendations			
		Food Modification	Personnel-related	Environment	Other
(Brooke & Ojo, 2015) United Kingdom	Clinical Review	Proper texture modification, energy dense menu items, and use of nutritional supplements to increase nutrient intake	Enhanced assessment and dietetic support to improve nutritional care Education and training of care staff in proper monitoring of resident intake and in strategies to assist in feeding	Create a pleasant environment to support eating, including proper lighting, use of ambient music, colour distinctions in place settings and utensils in order to aid visual cues	
(Douglas & Lawrence) United States	Narrative Review		Provision of specialized training for assistance in feeding to increase intake	Dining room ambiance improvements including homelike décor, use of tablecloths, contrasting coloured dishes, ambient lighting, use of music, pleasant cooking aromas, to increase QoL and intake	Bulk foodservice delivery of meals as opposed to tray service to increase intake Family-style dining to increase QoL and intake
(Dunne, 2010) United Kingdom	Clinical Review	Provide nutrient-dense choices to increase nutrient intake Fortify foods to maximize nutrient content	Provide assistance with meals to increase eating	Modify food delivery and presentation (e.g., soup in a cup, finger foods) to encourage independence in eating as much as possible Provide food frequently to increase opportunities for intake	

(Dunne & Dahl, 2007) Canada	Critical Review	Increase energy density in menu items offered Fortify foods to increase nutrient density of diet		Increase meal frequency to provide more opportunities for nutrient intake	
(Keller, Gibbs, Boudreau, Goy, Pattillo, & Brown, 2003) Canada	Intervention Research	High energy, high protein menu to increase weight gain and prevent weight loss	Enhanced RD time to assess and monitor residents		
(Liu, Cheon, & Thomas, 2014) United States	Systematic Review	Use of nutritional supplement to increase intake	Training programs for staff in nutritional care to increase intake Staff training in Montessori methods of care to increase independence in eating and QoL Staff training in individualized assistance at mealtimes and snacks to increase intake	Use of relaxing music to increase intake Use of contrasting coloured dishes to increase intake	Bulk foodservice delivery to increase intake
(Smith & Greenwood, 2008) Canada	Observational Review	Use finger foods to combat apraxia and texture modified foods to address dysphagia Use oral nutrition supplements to increase intake		Improve mealtime environment to reduce BPSD and improve food consumption	

(Ullrich, McCutcheon, & Parker, 2011) Australia	Intervention Research		Have care staff assist with meals to help encourage eating Have nurses supervise and guide staff on eating assistance technique		Create protected mealtimes to reduce distraction and preserve fidelity of dining experience
(Vucea, Keller, & Ducak, 2014) Canada	Scoping Review			Create a physically and psychosocially homelike environment to increase pleasure at mealtime and improve intake	

It is important to note that dementia is typically irreversible and fatal. Enhancing nutritional status of LTC residents with dementia is aimed at enhancing QoL by preventing unnecessary suffering from malnutrition complications such as painful pressure ulcers or infections. As well, dementia is rarely listed as a primary cause of death. In a study of 890 LTC residents with dementia in the Netherlands, immediate cause of death was listed as cachexia/dehydration (35.2%), cardiovascular disorders (20.9%), acute pulmonary diseases (20.1%), unknown cause (8.9%), and other causes such as digestive, urinary, or respiratory system diseases, cancer, and infectious disease (14.9%) (Koopmans et al., 2007). Harwood (2014) cautions that malnutrition at the very advanced stages of dementia may not be preventable, but notes that poor nutrition care may worsen dementia (Harwood, 2014).

The Alzheimer Europe recommendations for end-of-life care for persons with dementia suggest that decisions to discontinue feeding and hydrating should be entered into well in advance of the end of life, with emphasis on the person dying as a result of dementia not as a result of starvation (Gove et al., 2010). The recommendations include a note that manual feeding is time-consuming but caution that decisions to discontinue feeding should not be influenced by organizational issues such as staffing levels or workload. These recommendations also name RDs as healthcare professionals who should be involved in the coordinated care of persons with dementia, underscoring the importance of nutrition care expertise to end-of-life care for those with dementia (Gove et al., 2010).

Ensuring that LTC policies and practices to prevent weight loss and decline among LTC residents with dementia are consistent with person-centered care philosophy, and enhance rather than detract from resident QoL, may be an appropriate responsibility for dietitians (RDs). In addition to assessing residents' nutritional status and developing individualized nutrition care

plans, dietetic practice can more broadly encompass person-centered care through provision of education and training to all LTC staff and participation in interdisciplinary care teams for residents with dementia.

2.4 LTC Care Staff and Dementia

2.4.1 Care Aides and Nurses

The majority of care work performed in LTC is done by care aides, also known as personal care workers, health care aides, care assistants, nursing assistants, or personal support workers. Under the supervision of nurses, care aides provide the majority of personal care and ADL support within LTC. In SK LTC, care aides require completion of a Continuing Care Assistant certificate course to be completed within 24 months of their hire date. For those care aides who do not complete the certificate prior to beginning work, the majority of training happens ‘on the job’. Care aides are unregulated in Canada, meaning that there is no professional body governing care aide conduct or practice, or with whom the public could register formal complaints.

Because no national or provincial registries exist for care aides, very little is known about care aides as a labour force (Berta et al., 2013). A recent study of care aides working in LTC in the prairie provinces found that in general, LTC care aides are predominantly middle aged or older females with high school diplomas and some certificate-level care aide training (Estabrooks et al., 2015). This study found that in SK, 97% of the care aide workforce was female, 53.6% were between ages 40-59, 76% were born in Canada, 76% spoke English as their first language, and the average number of years working as a care aide was 11.8 (Estabrooks et al., 2015).

Nurses and care aides are well-positioned to monitor nutritional status and intake in LTC as they have the most direct contact with residents and can best assess changes in abilities or changes in

intake over time (Lou et al., 2007). While nurses assume responsibility for the proper implementation of the resident care plan, the care aides are responsible for the direct care to achieve the goals of the care plan. For example, nurses may be responsible for monitoring residents' nutritional status while care aides are responsible for directly assisting residents with eating and drinking. In a recent study of LTC staff attitudes to dementia, addressing eating problems was the ranked third among challenges experienced by nurses and care aides, after aggression and wandering (Lee et al., 2013).

Despite responsibility for nutrition related ADLs and personal care, care aides often have little training on nutritional care and rely on task-specific feeding practices germane to the institutional culture of LTC rather than person-centered care feeding assistance (Pelletier, 2005; Sidenvall, 1999). Reliance on routine has been reported as a coping mechanism among LTC staff facing a high demand for care within an unpredictable care context (Cammer et al., 2014). In a study of 48 nurses and 143 care aides that examined conceptualization of resident food refusal in LTC, few reported looking beyond the refusal or trying to find the cause of the refusal, and instead focused on how to accomplish the task of feeding (Norberg et al., 1988). Gibbs-Ward and Keller (2005) found that when care aides were able to shed their task-orientation and focus instead on activities related to mealtime assistance, the therapeutic and social aspects of meals were enhanced for residents with dementia (Gibbs-Ward & Keller, 2005). The rote processes of feeding a resident may fit well with a rigid institutional routine with predetermined times and deadlines for completion of care 'tasks', but this approach violates the principles of person-centered dementia care where feeding assistance that encourages resident participation and independence and intake of nutrients are valued equally. A study by Knopp-Shihota et al. (2015)

found that 86% of care aides feel rushed during their work, and 62% of care aides reported rushing while feeding residents (Knopp-Sihota et al., 2015).

An in-depth examination of care aides and assistant nurses' explanations for limiting choice or behavior of LTC residents found that the justification was rooted in how care aides valued an issue or complaint, and complaints about food or eating were often dismissed as trivial. The authors hypothesize that constructing an issue such as food complaint as trivial or insignificant serves to justify dismissal of the complaint and inaction (Persson & Wästerfors, 2009). Over time, such dismissal could accrue and have a large impact on nutritional care and resident health. Attitudes and behaviours related to nutrition care for LTC residents may be impacted by education and training. Pearson and Fitzgerald found that nursing staff were not attuned to how nutritional care processes at mealtimes affected residents' quality of life, and a key recommendation from that study was the creation and distribution of education materials to increase awareness and understanding of the importance of mealtimes (Pearson et al., 2003). Additionally, Reimer and Keller found that care staff had limited training on mealtime care and there was a need for staff training programs to accomplish person-centered mealtimes (Reimer & Keller, 2009).

Efforts to increase knowledge of nutrition care, particularly feeding assistance, for LTC residents with dementia have been made with the goal of enhancing resident health outcomes. An Australian survey of LTC staff knowledge of nutritional needs of LTC residents found a relatively poor knowledge score among all staff (47%) and among nurses (55%), with particular shortcomings on knowledge of hydration and nutrition needs related to pressure ulcers (Beattie et al., 2014). After completion of a training education session on feeding skills for working with LTC residents who have dementia, improvements in knowledge and attitude were measured

among care aides, and also in observed care behavior (Chang & Lin, 2005). Suominen et al. (2007) found that prior to an education intervention, nurses and food service workers did not understand the direct connection between nutrition and overall health of residents (Suominen et al., 2007). After completing intensive nutrition training sessions with a nutritionist (RD), these study participants were surprised to learn how much they had previously underestimated resident energy intake; prior to the intervention no residents met their recommended energy intake but after the intervention 29% met the requirement (Suominen et al., 2007). RDs can provide nutrition education and training to increase the abilities of care staff in LTC, which is of particular importance to care aides who provide the majority of direct personal care and are well-positioned to monitor change in resident eating ability and intake.

The role of care aides has evolved in recent years alongside the increased acuity of resident illness in LTC. Knopp-Sihota et al. (2015) note that most physical health needs and increasingly psychosocial needs are addressed by care aides within LTC (Knopp-Sihota et al., 2015). Care aides report having little control over how they perform care in the face of institutional routines and policies in LTC, particularly regarding care for residents with dementia (Morgan et al., 2012). Berta et al. (2013) report that increasingly, care aides are being delegated more care tasks and are asked to function within an interdisciplinary collaborative team setting, a role for which they receive little training or support (Berta et al., 2013). However, interdisciplinary team collaboration is heralded as the ideal to care for residents with dementia who “have complex needs requiring a sophisticated, multidisciplinary approach to care” (Hirdes et al., 2011).

2.4.2 Registered Dietitians

The complexity of care needs for LTC residents with dementia requires an interdisciplinary approach, with support from allied healthcare workers such as RDs, physical therapists,

occupational therapists, and social workers. However, support within LTC by allied professions is extremely limited. A recent study showed that SK has very few allied health care providers or specialists providing service in LTC in comparison to other prairie provinces examined (Estabrooks et al., 2013). This is particularly true for RDs. A recent survey in SK found that RD coverage in LTC amounts to approximately 7 minutes of clinical RD time per resident per month (LTCAG, 2015). In comparison, Ontario has a legislated requirement of 30 minutes of RD time per resident per month while no provision for RD time is made in SK (Ontario Ministry of Health, 2010; Saskatchewan Health, 2013). RDs often occupy a consultant role to LTC rather than a staffed role. That is, fewer RDs practice solely in LTC and are instead may practice as a community outpatient RD who receives referrals to provide expert consultation on a particular resident case (Batchelor-Aselage et al., 2015).

As experts in nutrition, RDs can assist in menu and recipe development to support the nutrient requirements of LTC residents, help to design appropriate eating environments, design nutritional interventions, complete comprehensive nutritional assessments and create nutrition care plans specific to each resident, develop therapeutic diets or adapt diets to fit the needs of residents, support and educate other care staff in nutritional care, act as advocates, and actively contribute to interdisciplinary care teams (Batchelor-Aselage et al., 2015; Black et al., 2013; Ducak & Keller, 2011; Jurkowski, 1998; Lilley & Gaudet-LeBlanc, 1992; Wassink & Chapman, 2010). Comprehensive nutrition assessment and care by RDs has been shown to prevent weight loss among residents with dementia (Keller et al., 2003). RDs have been shown to be effective in helping LTC staff to shift from task-based feeding to a person-centered care approach as it relates to nutrition (Gibbs-Ward & Keller, 2005). As well, RDs can actively demonstrate person-

centered care and contribute to positive culture change within LTC (Wassink & Chapman, 2010).

RDs can provide the expertise in nutrition care necessary to an interdisciplinary care plan for LTC residents, particularly when managing weight loss, undernutrition, and dementia (Salva et al., 2009). A 2005 study in a Canadian LTC setting found a significant discrepancy between weight loss assessments made by nurses and a RD when using information from the same medical charts (Bowman & Keller, 2005). Findings from this study also suggest that the LTC RAI-MDS screens for resident malnutrition risk alone are not adequate, noting that cognitive status is not included in the nutritional risk section despite the established connection to lowered nutritional status (Bowman & Keller, 2005). RD involvement in developing LTC screening policies and procedures as well as training of staff may be beneficial.

A Canadian study of RDs working in LTC found that the RD role is not pre-defined and is instead very independently determined; the RD may have specific duties at the LTC and particular responsibilities within the care team, but the structure of the job was largely designed by the RD (Wassink & Chapman, 2010). This same study found that despite having no formal staff supervision duties, RDs often assumed a leadership role within LTC, actively engaging staff and motivating them in person-centered care as it applied to nutrition care and also more broadly (Wassink & Chapman, 2010). However, another Canadian study of RDs working in LTC found that RDs experienced extreme challenges, mainly related to time constraints due to part-time work and low staffing level of RDs (Black et al., 2013). Of the 75 LTC RDs surveyed, only 44% worked full-time hours, 57% held more than 1 LTC RD position, and 44% reported insufficient time to accomplish required tasks. Notably, despite 75% of those surveyed expressing desire to remain in the province for the duration of their careers, 20% expressed intent to leave LTC

dietetics and 44% reported being undecided (Black et al., 2013). As well, a 2008 study of recent graduate RDs and RD internship supervisors revealed a devaluation of the RD role in LTC compared to acute care, noting that the LTC holistic approach and focus on resident quality of life was dismissed and viewed as a focus on ‘extras’ (Lordly & Taper, 2008).

The nature of person-centered care in the LTC setting demands a broad conceptualization of ‘expert’ as all care staff play an essential role in designing and executing care. RDs occupy a valuable role on interdisciplinary LTC teams as experts in nutrition, but need to keep a broad perspective that nutrition care is not simply delivery of nutrients in appropriate form and quantity. As Lilley and Gaudet-LeBlanc (1992) aptly stated,

“As dietitians we sometimes forget that meeting nutritional requirements is not an end in itself, but a means of improving or maintaining an individual’s quality of life. ... The long-term care facility offers the dietitian a unique opportunity to observe the client in his or her everyday life, and forces us to come to terms with the feasibility, impact, and results of our practice. To the extent that we can contribute to promoting the self-esteem and independence of the residents in areas relating to food and nutrition we are contributing to nutritional care.”(Lilley & Gaudet-LeBlanc, 1992)

While there is still very little research reported on the role of dietitians in LTC it is especially noteworthy that no published studies could be found on the role of RDs in dementia care. RDs have the ability to develop and translate person-centered care practices specific to nutrition to other care staff, and the ability to deconstruct complicated issues particular to nutrition care for residents with dementia such as interaction due to comorbid conditions or hand feeding versus tube-feeding. With the growing body of evidence regarding nutritional implications of BPSD and the increased prevalence of dementia, particularly within LTC, dietetic care and dementia is an area worthy of significant investigation.

2.5 Evidence-based Practice

Evidence-based medicine (EBM) is defined as “conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patient” (Sackett et al., 1996). EBM “...requires a bottom up approach that integrates the best external evidence with individual clinical expertise and patients' choice” (Sackett et al., 1996). EBP is the term often used when speaking more broadly about use of evidence by healthcare practitioners, and not specifically regarding physicians and the practice of medicine. Guyatt, et al. note in the preface to ‘Users’ Guide to the Medical Literature: A Manual for Evidence-based Clinical Practice’ that EBM principles are equally applicable to other healthcare providers’ practices, so the more inclusive EBP term can be used to refer to any evidence-based approach to healthcare practice (Guyatt, 2008).

EBP is rooted in the work of Dr. David Sackett who developed a model made up of three components essential to EBP: “(1) Consideration of the patient’s expectations (wishes); (2) our clinical skills; and (3) the best evidence available to us” (Thoma & Eaves, 2015). To understand Sackett’s model of EBP functioning successfully in healthcare it is useful to envision care as the seat of a stool with each of the three EBP components representing a leg of the stool. The purpose of the legs is to support the seat and the stability and strength of the entire stool is compromised when any of the legs is lacking. In an interview on EBP, Guyatt emphasized that evidence alone does not determine care decisions or processes; instead evidence must be considered within the context of values and preferences (Guyatt & Voelker, 2015).

The shared decision making between the patient and healthcare team is an important characteristic that distinguishes EBP from straightforward application of evidence. The patient must be knowledgeable and understand care options in order to make an informed decision, and

the role of the healthcare practitioner lies in translating the care options to the patient while respecting individual values and beliefs. Guyatt noted that an informed individual is able to make the distinction that undesirable consequences outweigh desirable consequences (and vice-versa) based on their personal set of values and preferences (Guyatt & Voelker, 2015).

Within the context of LTC, EBP can be viewed as a successful integration of person-centered care (patient values and preferences), executed by competent skilled staff (clinical expertise) whose work is governed by best practice standards and policies (research evidence, practice guidelines derived from research evidence). Specht (2013) noted that EBP in LTC can help to make best use of limited resources because EBP-rooted care has a higher likelihood of effectiveness (Specht, 2013). A complicating factor in the successful application of EBP in LTC is dementia and the ability of residents with dementia to actively and fully engage in decisions regarding their own care. In a 2003 article on EBP using case examples from dementia care in Australia, Nay noted that in order to improve actual resident outcomes, an EBP care approach must be rooted in the care context, and informed by resident preference and clinical judgements which are based on individualized care plans (Nay, 2003). The information contained in resident care plans is often heavily relied upon when the resident is unable to communicate preferences or values.

Barriers to EBP include lack of resources, time limitations, perceived lack of authority to make changes, lack of support from leadership, and lack of skill in interpreting research (Chang, Russell, & Jones, 2010; Gerrish & Clayton, 2004; Specht, 2013). McConnell et al. (2007) reported that most LTC homes do not have policies or supports in place to facilitate EBP, such as processes to assist with review of evidence and processes to aide in systematic adoption of new practices (McConnell et al., 2007). Their assessment that the relatively isolated professional

setting of LTC paired with the relatively low proportion of RNs employed in LTC contributes to the difficulty of operationalizing EBP in LTC. They instead advocated for an academic-practice partnership to facilitate EBP in LTC. Chang et al. (2010) also found professional isolation to be a challenge in implementing an EBP approach in LTC (Chang et al., 2010).

The paucity of research evidence to inform practice in LTC is an impediment to successful EBP. Rolland and de Souto Barreto (2013) note that the current care strategies or therapy protocols used in LTC rely on little research evidence, largely because research is not conducted with the LTC population, and is instead conducted with community-dwelling older adults or older adults patients in acute care settings (Rolland & de Souto Barreto, 2013). After conducting a Medline search, these authors concluded that only 2.5% of studies in older adults have been conducted within the LTC context (Rolland & de Souto Barreto, 2013). Of the four priority areas identified from the 2010 workshop of the International Association of Gerontology and Geriatrics taskforce, one was advocacy for a LTC research agenda. The group was explicit in valuing EBP, and stated that they interpret EBP to be a right of those living in LTC, that those living in LTC have a right to care that is based on the best available evidence (Tolson et al., 2011). Among the 15 recommendations included in the report were two advocating for research in LTC, Recommendation 14 (Develop nursing home research capacity in developing nations) and Recommendation 15 (An investment is made in research priorities that address major public health problems and inequalities that affect older people receiving long-term care) (Tolson et al., 2011). This international commitment to EBP and an increased research agenda in LTC is timely and essential.

In a survey of 19 experts in LTC from 8 countries, the top two issues identified as priorities for future research needs in LTC were dementia care and psychosocial interventions for BPSD

(Morley et al., 2014). Notably, the fourth-ranked issue was improving nutrition in LTC and the sixth was putting evidence-based care into practice (Morley et al., 2014). Because of its centrality to LTC resident health and QoL, nutrition care is an essential area for EBP efforts. Efforts to better understand the state of the evidence for best practices in nutrition care for LTC residents with dementia, how care aides can best provide nutrition care for residents with dementia, and the role of the RD in dementia care in the LTC setting will increase the ability to design EBP policies and practice guidelines.

2.6 Integrated Knowledge Translation and Exchange Research

Central to the effectiveness of EBP is knowledge translation and exchange (KTE). KTE can be viewed as a strategy for engaging with decision-makers and stakeholders outside the traditional research team in order to improve the quality and accelerate the uptake of research products, or translation of research into practice (Graham et al., 2006). According to CIHR, KTE is “a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system” (CIHR, 2014). KTE can be conceptualized as communication and sharing of information and ideas between agencies, levels, or provider groups, making it a critical aspect of EBP in healthcare. Zoellner et al. (2015) note that translational research requires perspectives of multiple stakeholders as well as a collaborative approach (Zoellner et al., 2015). A team of researchers in Toronto assert that continuing medical education and continuing professional development efforts, which are typically passive education efforts (i.e. didactic delivery of information), are not effective in creating change in healthcare practice and argue that KTE is an important tool that is better able to bridge the gap between evidence and practice (Davis et al., 2003).

Integrated KTE consists of engagement with knowledge producers, decision makers, and knowledge users in a more involved manner than one-way, straightforward dissemination of research evidence with a low level of stakeholder engagement. Instead, integrated KTE is focused on mutual learning processes and actively values the input of key groups early and often in the research process, using input from these stakeholders to shape research questions, strategies for research engagement, data collection, and application of findings (CIHR, 2012). Working with stakeholders to determine not only how to study a particular issue but also how to communicate the findings into practice improvements is a strength of KTE research, and increases its utility in EBP.

Another key element of KTE is thoughtful consideration of the users of the research and their needs in terms of communication of findings. Tailoring communication of findings to a particular audience can be a key asset of KTE, particularly in the field of LTC where unskilled care aides have limited ability to access or interpret traditionally produced research evidence. For example, Janes et al. (2008) found that care aides engage less with printed resources or guidelines the way that trained healthcare professionals may, but instead rely on verbal discussions and experiential learning to develop best practice knowledge (Janes et al., 2008). As well, Zoellner, et al. (2015) recognize that as essential members of multidisciplinary health teams, RDs can help expedite translation of nutrition research into EBP (Zoellner et al., 2015). An integrated KTE strategy, with thoughtful consideration of end users such as RDs and care aides, can increase the impact of research and ensure expedited uptake of research into EBP (CIHR, 2012).

2.7 Qualitative Methodologies

Qualitative research is inductive and seeks to gain understanding of issues not easily quantified.

“When phenomena are not easily measured, processes must be evaluated, knowledge is limited about a culture, or reasons must be discerned for outcomes a [qualitative approach] is warranted” (Harris et al., 2009). In large part, qualitative inquiry is focused on human experiences, and the underlying nature of these experiences (Draper, 2004). Morse (2012) argues that qualitative health research has two defining features, focus and methods, where focus refers to the study of health from an experiential lens and methods refers to the use of non-numeric data collected within a particular context determined by the health issue being examined (Morse, 2012).

Harris and Beto (2009) propose nine purposes for qualitative research: to determine causal explanations of phenomena in their natural settings, to study the process or natural history of a phenomenon, to understand the culture, traditions, symbols, perception, emotions, language, and meaning of phenomena to participants, to describe the context of phenomena, to complement quantitative research, to generate tentative theories and hypotheses, to describe unfamiliar community or culture, to validate theory, and for formative evaluation (Harris et al., 2009).

Morse (2012) similarly defines the domain of qualitative health research as made up of nine categories: identification of health care needs, examining processes of seeking healthcare including barriers and access to care, exploring the illness experience, trajectories of recovery from illness; living with a disability, mental or physical, behaviors and experiences of professional care providers, research that contributes to the examination of health care professions, health care evaluation, policy, and program development, evidence-based practice, and development/modification of qualitative methods (Morse, 2012, p. 34).

Qualitative methods are useful for developing an understanding people's experiences and determining patterns that can deepen our appreciation of a phenomenon or experience (Fade and Swift, 2011). As such, shared individual, group, and contextual factors are important considerations in qualitative studies (Harris, 2009). Findings from qualitative research are often focused on developing theoretical understandings or developing concepts (Draper, 2004). Because issues of nutrition care processes for dementia care in the LTC setting are at a developmental stage, and the roles of care aides and RDs with respect to nutrition and dementia care are not described in current literature, qualitative inquiry is the best fit for investigation in this area.

Chapter 3.0: Methods

The studies that comprise this doctoral research are united under an evidence-based practice (EBP) framework, and an integrated knowledge translation exchange (KTE) approach. There is a need for studies investigating the role of both care aides and RDs in LTC, particularly regarding care for residents with dementia, the role of care aides and RDs on interdisciplinary care teams in LTC, and the relationship between RDs and care aides in providing person-centered nutrition care for residents with dementia in LTC. To accomplish this, qualitative methodology was used.

Three studies comprise this research: 1) an investigation of the role of nutrition care for LTC residents with dementia from the perspective of care aides, using focus group discussions to generate data and framework analysis methods; 2) an examination of the role of RDs in nutrition care provision for LTC residents with dementia from the perspective of RDs practicing in LTC, using in-depth interviews to generate data and grounded theory analysis methods; and 3) an umbrella review of the current state of peer-reviewed evidence surrounding nutrition care for LTC residents with dementia, using review methods to collect and analyze data from published peer-reviewed systematic reviews. A description of EBP, KTE, and qualitative methods specific to this doctoral research follows.

3.1 Knowledge Translation and Exchange Committee

In this research, an integrated KTE model was used. A team of three decision-makers was formed prior to undertaking the research. The three decision-makers were RDs: one working in a predominantly clinical role in LTC, one working in a predominantly foodservice role in LTC, and one working in an out of scope managerial role. The group met regularly to discuss the proposed research, the research process as it unfolded, as well as post-research translational strategies. At each step in the process the team provided input, gave suggestions, and helped to

shape the research to be useful in terms of LTC practice. As well, preliminary research was shared with the KTE decision-makers and various groups in continuing education presentations, and the committee suggested non-academic audiences to communicate the research findings.

3.2 Care Aide Study

The first study in this doctoral research is an examination of nutrition care for LTC residents with dementia from the perspective of care aides with attention paid to the rural LTC context and its impact on this care. With guidance from the KTE committee, four LTC homes within one health region were selected and invited to participate in the research project. The homes were chosen as examples of the most typical LTC within the province in terms of number of residents and operational models. Two of the homes were located in an urban setting and two were located in rural settings, as per the Statistics Canada “rural and small town” definition of rurality, those communities outside of the commuting zone of centres with populations of 10,000 or more (Statistics Canada, 2011c). Each of the LTC were in situated in towns over 250km from the nearest urban centre.

The KTE committee facilitated meetings between the researcher and the Seniors Health and Continuing Care department that provided direction and oversight to the LTC within the region. The researcher presented the proposed research project to this group and the LTC Administrators and Directors of Care at one of their quarterly meetings, then extended an invitation to the 4 LTC homes identified as most appropriate. Following this, meetings were held with each LTC Administrator or Director of Care to seek formal agreement to participate in the research. Each LTC allowed the care aides to participate in the research project during their work time. The best time of day and date that the LTC could accommodate the research was predetermined

and posters advertising the research project were displayed within the LTC for 2 weeks prior to data collection, were distributed to care aides in their personal work mailslots, and were discussed during their regular staff meetings, including a reminder on the days when data collection was scheduled. Care aides were encouraged to participate even if not scheduled to work on the dates when focus group discussions were being held, but no care aides participated outside of their work hours. Data generation occurred between May and July 2015.

Focus group discussions were used in this study to generate data and analysis was performed according to framework analysis methods. Morgan's method of focus group discussion recognizes the active role of the researcher in framing the discussion in order to collect research data (Morgan, 2004). Morgan supports the idea that the interaction between group members within the focus group discussion is a valuable source of data, noting that this is less ideal when participants are discussing a highly personal or sensitive matter that may limit comfort with disclosure and discussion (Morgan, 2004). Focus groups are useful for working with participants from marginalized groups, or with limited literacy or confidence in the dominant culture and language (Gray, 2014). Krueger (1994) notes that focus groups can help to mitigate existing power differences between professionals/researchers and research participants (Krueger, 1994). Gray (2014) states that focus groups are an ideal method for exploratory discussion of shared and unshared attitudes or experiences (Gray, 2014). Interaction of participants within focus groups adds a depth to the data that might not be accomplished via individual interviews. Morgan states:

“[The] ability to observe the extent and nature of interviewees' agreement and disagreement is a unique strength of focus groups. A further strength comes from the researcher's ability to ask the participants themselves for comparisons among their experiences and views, rather than aggregating individual data in order to speculate about whether or why the interviewees differ” (Morgan, 2004), p.272.

The focus group method helps to create a safe environment in which to engage, and reduces the hierarchical nature of researcher-researched. These attributes make focus group discussions an ideal method to generate data with the LTC care aide population. Care aides make up a distinct group with shared characteristics and ability to comment on their experiences and perspectives, and may feel better able to voice their experiences to a researcher within a group setting.

Rabiee's outline of framework analysis guided the data analysis of the focus group discussions (Rabiee, 2004). Framework analysis involves five stages of analysis of qualitative data: the first stage is full familiarization with the data through transcript review and listening to recordings with the aim of gaining a broad appreciation for each focus group discussion as a whole before breaking the data apart. Next a thematic framework is developed that is similar to open coding of data followed by a process of indexing the data where concepts are organized and comparisons among concepts made. The fourth stage is charting of findings where thematic content is organized and mapped. Finally, in the fifth stage the content is analytically interpreted and written as thematic findings (Pope, 2000).

3.3 Registered Dietitian study

The second study in this doctoral research is an examination of the role of the RD in nutrition care for residents with dementia in LTC, with attention paid to the rural context and its impact on the LTC RD role. RD participants were initially sought via the Saskatchewan Dietitians of Canada LTC Action group membership list, then via suggestions from the KTE committee. Individual RDs were approached directly by the researcher via telephone or email and invited to participate at a time and location convenient to the RD. This project was completed according to constructivist grounded theory methods. Data were generated through a combination of in-person and telephone interviews between November 2015 and February 2016. Though the intent was to

conduct all interviews in-person, inclement weather prevented this. Participants were given the option of rescheduling or participating in the interview via telephone.

Interviews are a common method of qualitative data generation. The purpose of an interview is to gain an in-depth understanding of another's expertise, perspective, and experience (Quinn Patton, 2002). Strengths of interviews include depth of discussion, flexibility in questioning and resultant ability to explore new and emerging themes, and ability to encompass a wide variety of topics, while disadvantages include their time-consuming nature, and dependency on the skill of the researcher to successfully guide the interaction (King, 2006; Quinn Patton, 2002). Charmaz proposes use of 'intensive interviewing' style for grounded theory studies, which uses open-ended questioning of a pre-determined, focused topic to elicit detailed responses from participants that include their perspectives and experiences, for the purpose of in-depth understanding of the research question (Charmaz, 2014). Charmaz notes that intensive interviewing draws on informational interviewing (to gain facts) and investigative interviewing (to uncover hidden actions or intentions) but also allows for interaction between the researcher and participant to explore unanticipated information or meanings (Charmaz, 2014).

Charmaz's constructivist grounded theory methods are inductive and rooted in symbolic interactionism, positing that data is generated rather than collected (Charmaz, 2006). A key components of grounded theory analysis is the use of constant-comparison method throughout the data generation and analysis processes (Glaser, 1978). Constant comparison refers to the process where analytic comparisons are made between pieces of data, between data and codes, between memos and data, and between levels of codes, for example. Constant comparison process helps to systematically refine data and ensure that findings are rooted in the data.

As a data collection method, grounded theory style individual interviews enable a deep exploration of issues with the ability to be flexible and adapt the questioning to pursue new insights as they are introduced by the participant. As well, the embedded constant-comparison grounded theory technique allows for tailoring of each subsequent interview to build on concepts learned and develop more refined exploration of topics. As such, constructivist grounded theory methods allowed for a deep conceptual understanding of the RD role that is rooted in the RDs' experiences and contexts.

3.4 Umbrella Review

The last project in this doctoral research is an examination of the formal literature that underscores EBP of nutrition care for residents with dementia in the LTC setting via an umbrella review. A systematic review is used to answer a research query by methodically searching the peer-reviewed evidence, critically appraising the quality of that evidence, and assembling it into a coherent summary (Khan, 2011). Similarly, an umbrella review is a rigorous examination of systematic reviews in pursuit of a broad, conceptual understanding of what is known about a particular topic with attention paid to gaps remaining in the current evidence base (Grant & Booth, 2009).

Reviews can be a cornerstone of EBP; peer-reviewed publications are collected, interpreted, and distilled to address a discrete area of interest and summarize the current state of the knowledge, and this distillation can be used to guide decision making for policy effort or patient care.

Generally, a review is structured in a step-wise progression beginning with definition of the question, followed by a thorough search of literature, application of explicit inclusion and exclusion criteria, analysis of study findings including assessment of quality, then summarizing the findings for uptake and application (Guyatt, 2008; Khan, 2011).

The intent of this umbrella review was to ascertain what is currently reported in the peer-reviewed systematic review literature regarding nutrition care for residents with dementia in the LTC setting. As well, the current state of the literature was assessed to determine whether there is general consistency regarding interventions or outcomes considered in the literature. Last, this body of literature was examined to determine what recommendations were made specific to RDs and care aides in terms of their roles or practices related to nutrition and dementia care.

The following chapters 4, 5, and 6 of this thesis are in-depth descriptions in manuscript-style format of each of the three studies that comprise this doctoral research. Following these chapters is a discussion chapter that addresses the overarching research findings.

Chapter 4: Nutritional Care for Residents with Dementia in Rural and Urban Long-term Care Homes: Perceptions of Care Aides

4.1 Background

Dementia is now recognized as a worldwide public health priority and the number of people with dementia is projected to double to 65.7 million by 2030 (WHO, 2012). The current population demographics and increasing prevalence of dementia have significant impact on need for formal care. Dementia is the top chronic condition necessitating placement in long-term care (LTC), and residents with dementia require more direct-care time compared to those without dementia (Prince, et al., 2013). Within Canada, it is estimated that between 45 - 60% of LTC residents have a diagnosis of dementia and dementia is the second most common health condition experienced within LTC, after bladder incontinence (CIHI, 2013; Wong, 2016). Persons with dementia are less able to perform activities of daily living (ADLs), such as eating and drinking and nearly 20% of Canadian LTC residents with dementia were rated completely dependent in ADLs (CIHI, 2010).

Nutritional health of LTC residents with dementia is central to quality care. Physiological changes in residents with dementia, such as reduced hunger and thirst cues, difficulty in mastication, swallowing, and digestion can negatively impact nutritional intake, while behavior changes such as repetitive actions and chronic wandering can increase nutritional needs. Combined, these factors contribute to a higher risk for malnutrition in residents with dementia which in turn predisposes them to adverse health outcomes such as muscle wasting, infection, poor wound healing, loss of sensory function, reduced cognitive ability and reduced quality of life (Chen et al., 2001; Mitchell et al., 2009; Smith & Greenwood, 2008). Optimizing nutritional status can reduce disease co-morbidity and prevent accelerated decline in physical health (Keller

et al., 2003). While nutrition intervention may not reduce dementia mortality, it could help to delay disease progression and benefit resident quality of life (Prince et al., 2014).

Despite the risks associated with malnutrition, nutrition care is not well regulated in LTC homes; standards and practices can vary between and within facilities or even within care provider category. Within LTC, the majority of resident care is provided by aides who have limited training in both nutrition and dementia and rely on task-specific nutrition care (Pelletier, 2005). Rural LTC facilities may be further disadvantaged due to limited access to specialist care including dietitians to aid in resident-centered diet, intake, and feeding guidance. Residents with dementia face problems with oral intake and nutritional status due not only to the physical disease progression but also due to care, as staff in LTC report difficulty in food provision and feeding residents with dementia (Pasman et al., 2002). Current practice recommendations for nutrition care in LTC do not address dementia (DC, 2013).

Givens et al. found that the majority of decisions made by healthcare proxies of persons with dementia were regarding management of eating and drinking problems, not surprising considering the high rate of nutrition-related activities of daily living difficulty among persons with advanced dementia (Givens et al., 2009). A study by Mitchell et al. found that 86% of nursing home residents with dementia developed difficulty with eating (Mitchell et al., 2009). The majority of direct care involving eating, drinking, and feeding assistance within LTC is completed by care aides. Nutrition care, particularly meal provision, is often routinized and task-focused (Sidenvall, 1999) rather than person-centered and encompassing of best practices for resident care (Brooker, 2007; Murphy et al., 2017).

Care aides, also known as continuing care assistants, personal support workers, nursing assistants, or nursing aides, provide the majority of direct care within LTC homes. As such, they

are responsible for delivering much of the nutritional care, especially mealtime assistance that a resident with dementia receives. However, little is reported from the perspective of care aides regarding nutritional care for LTC residents with dementia. Innes notes that the field of dementia research has typically ignored "...the views and experiences of paid carers who tend to lack formal qualifications and the associated link with a professional body, who hold low status within the workplace and who may experience marginalization within the workplace due to their gender, ethnicity and class" (Innes, 2009, p.106). Examining the principles of nutritional care for persons with dementia from the perspective of care aides is an important step in understanding the current state of nutrition care for residents with dementia in LTC, as well how to best communicate best practices and translate these into effective nutrition care.

Sackett's model of evidence-based practice is comprised of three key components: research evidence, clinical expertise, and patient values and preferences (Sackett et al., 2000). A useful analogy is to envision evidence-based practice as the seat of a stool with each of the components representing a leg of the stool; stability and strength of the entire stool is compromised when any of the legs is weak. Within the context of LTC, evidence-based practice can be viewed as a successful integration of person-centered care (patient values and preferences), executed by competent skilled staff (clinical expertise) whose work is governed by best practice standards and policies (research evidence). In many ways, care aides function to represent the person-centered care as well as the clinical expertise aspect of this EBP model as it pertains to nutrition care provision for residents with dementia in LTC, due to limitations of the residents to fully communicate their own personhood. With this in mind, examination of the nutrition care practices for residents with dementia in LTC from the perspective of care aides is timely, with opportunity to significantly inform resident care.

4.2 Methods

The objective of this study was to examine care aides' perception of nutrition care for residents who have dementia, and gain insight into what care aides consider optimal nutrition care or best practice.

4.2.1 Setting and Participants

Two urban and two rural LTC homes in the prairie province of Saskatchewan were sampled for participation in this study. The four LTC were identified through discussion with the senior staff in the Seniors Health and Continuing Care department of the Saskatoon Regional Health Authority (RHA). These homes represent common characteristics of LTC homes in general throughout the province in terms of bed-size (two of approximately 100 beds and two of approximately 50 beds), and organizational model (mix of public owned and operated and affiliate-run).

Ethical approval was received from the University of Saskatchewan Behavioural Ethics Review board (Beh 15-98), and operational approval was granted by the Saskatoon Health Region's review board. Administrators from each LTC gave approval for the project to proceed within their LTC, and allowed care aides to participate during work time. Posters advertising the date, time, location, and purpose of the focus group sessions were distributed to each LTC, and LTC nurses brought a copy of the poster to the staff communication briefing meetings to remind care aides on the day of the focus group session.

4.2.2 Data Generation

The exploratory nature of the research objectives led to use of qualitative methodology. Data for both objectives were generated through focus group discussions with care aides at each of the

two rural and two urban LTC homes. Participants were sampled by purposive sampling method, i.e., those care aides who were available at the time arranged as convenient to the LTC home for focus group discussion. Two focus group sessions were conducted at each LTC home.

Individual care aide participants completed an informed consent process immediately prior to data collection. This included a brief discussion of the focus group session, review of the consent form (included in Appendix 1), and signing the consent form. Aides then completed a basic demographic information form, were shown a 12 minute educational video on mealtime assistance, and the focus group discussion began immediately following viewing.

Morgan's method of focus group discussion was followed, recognizing the active role of the researcher in framing the discussion in order to collect research data (Morgan, 2004). Morgan supports the idea that the interaction between group members within the focus group discussion is a valuable source of data, noting that this is less ideal when participants are discussing a highly personal or sensitive matter that may limit comfort with disclosure and discussion (Morgan, 2004). Because the intent of this research was to assess views and work experiences germane to care aides within the LTC setting, comfort with disclosure should not be a limitation. Rather, the interaction of participants was an asset in this project and added a depth to the data that might not be accomplished via individual interviews. Morgan states:

[The] ability to observe the extent and nature of interviewees' agreement and disagreement is a unique strength of focus groups. A further strength comes from the researcher's ability to ask the participants themselves for comparisons among their experiences and views, rather than aggregating individual data in order to speculate about whether or why the interviewees differ (Morgan, 2004, p.272).

As well, the relative homogeneity of the group and established relationships among participants may have increased the comfort and safety in sharing views within the focus group discussion (Barbour, 2005).

4.2.3 Data Analysis

Focus group discussions were digitally audio-recorded then transcribed for analysis. Data analysis followed the process of Framework Analysis outlined in the article ‘Focus-group interview and data analysis’ (Rabiee, 2004). Thematic analysis was performed by one researcher (AC) and verified by another (DM). Data was analytically interpreted and organized into interrelated thematic categories. The trustworthiness or rigour of the study was assessed according to Shenton’s outlined strategies to ensure credibility, transferability, dependability, and confirmability of qualitative findings (Shenton, 2004).

4.3 Findings

Eight focus group discussions were held at two urban and two rural LTC with a total of 43 care aides. All LTC were co-located within one geographic health region, therefore there was homogeneity of overarching mission, vision, values, and overarching governing policies and procedures. Both urban had bed counts of approximately 100, while the two rural had bed counts of approximately 50, which was deemed representative of the urban and rural LTC settings. The two rural sites were both approximately 250km from a major metropolitan area. Demographic features are described in table 4.1.

Table 4.1: Demographic characteristics of care aide participants

8 focus group discussions; 43 care aides in total	
Urban LTC	Rural LTC
2 LTC homes, 4 focus group discussions	2 LTC homes, 4 focus group discussions
24 care aide participants (5/5/7/7)	19 care aide participants (8/4/4/3)
Sex: 23 female 1 male	Sex: 19 female 0 male
Work Status: 13 full-time 8 part-time 3 casual	Work Status: 12 full-time 5 part-time 2 casual
Continuing Care Assistance Course: 14 completed 9 not completed 1 in-progress	Continuing Care Assistance Course: 16 completed 3 not completed 0 in-progress
Mean length of employment as a care aide: 11.9 yrs (0.5 – 40.0)	Mean length of employment as a care aide: 10.8 yrs (0.5 – 24.0)

4.3.1 Thematic Categories

Framework analysis yielded six thematic categories addressing the care aide role and perception of nutritional care for residents with dementia in LTC setting. The challenges experiences and strategies used in accomplishing nutritional care are encapsulated within these thematic categories.

Table 4.2: Thematic categories – care aide study

	Operational	Experiential Learning -Studying versus ‘real world’ -Unable to predict or teach every scenario -Mentoring to increase competence and skill	Balancing Resident Care Needs -Care needs a ‘moving target’ -Balance and compromise -Knowing resident as crucial element to care	Operational Demands -Schedule and workload dictate care -Many residents, numerous care interactions -Between departments and amongst staff
	Theoretical	Coping Strategies -Alternate strategies developed to compensate when lacking human resources, tools, or knowledge resources	Operationalizing Person-Centered Care -Complex theoretical orientation to care -Multiple interpretations -Continually negotiated	Perception of Nutrition Care -Focus on physical and mechanistic aspects of nutrition care -Less attention given to psychosocial components

The categories are grouped into ‘Operational’ and ‘Theoretical’. The operational categories relate to day-to-day work practices surrounding nutrition care for residents with dementia as well as the immediate considerations that care aides undertake when performing nutrition care. The theoretical categories encompass more of the philosophical domains, and broader considerations related to nutrition care for residents with dementia.

4.3.1.1 *Experiential Learning*

Care aides perceive that training or studying in courses is not adequate preparation for ‘real world’ of nutrition care, particularly for those residents who have dementia. While they noted that training via the continuing care assistant course or continuing education sessions was a good way to learn about dementia generally as a disease, they reported that the actual care required to provide adequate nutrition and hydration was not something that could be taught in a didactic manner. Aides noted that it would be impossible to teach every behavior or scenario that would be encountered, and also thought that it would not be feasible to effectively teach the balancing of care needs and competing demands ubiquitous to nutrition care.

“You need to see the real side of it. [Training is] nice, but it’s not like that in real time - It’s very chaotic, bringing people back to the table. It’s messy, you’re washing people, and you need to see the real side of it and see just how hard it is to get someone with dementia to eat or drink.”

As well, an aspect of unpredictability related to dementia was noted by care aides, which complicated nutrition care. Care aides described episodes of physical aggression from residents when assisting with eating and hydration, and credited experience as a factor that helped to predict and prevent future episodes of aggression.

“We have had water thrown at us. Spit at us. We have [combative behavior] at mealtimes.”

“[She’d] throw it in your face if she didn’t want it ...people throwing their food, jabbing people with their forks ... more aggressive.”

Overall, care aides perceived shadowing or mentoring as well as on-the-job experience to be the most effective ways to develop an understanding of nutritional care and to become proficient in providing care.

“Past care aides that have done it for 25 years showed us these little tricks that they learned over the years.”
“As you work more it becomes second nature.”

However, a downside to shadowing and experience as sole sources of training was expressed by care aides as well. Some noted that this puts pressure on senior staff, and allows for inconsistency, misinformation, or improper practices to be perpetuated and cemented into the work culture.

“What I find bizarre is these new people are hiredthey don’t get really much training, they don’t have any knowledge, they have to take their course within two years ...The damage could be done before you even got your course.”
“Having no knowledge whatsoever, that leaves a lot of onus on permanent employees that are trying to train them. And if they do something wrong ...say there’s four people training them, so you have four different types and then they’re all confused because everyone has their own little way of doing things, right? It’s not always consistent.”

4.3.1.2 Balancing Resident Care Needs

Meeting the nutrition care needs of residents with dementia, according to care aides, is extremely difficult due to the very nature of the disease. Care aides described seeking balance and compromise in the individual care in an effort to ensure that the primary needs of intake were met without exacerbating behavioural issues. The priority care need in a given moment is

perceived as a ‘moving target’; nutrition care needs must be continually evaluated and regrouped while considering how to best proceed.

“I mean, day to day it’s different – one day they could be afraid of something and the next day they’re not. It’s never the same with them, ever. It’s always different. You never know, you’re assessing all the time.”

“They change so much within ... you know, moods and stuff or ability to do stuff. Things that work for you one day don’t work for you the next day.”

“It can be different every day – it can be different two minutes from now!”

Repeatedly, the notion of ‘knowing the resident’ was asserted as the key strategy to successfully providing nutrition care. A solid understanding of the specific likes and dislikes of each resident with dementia were noted as crucial to inform good nutrition care. However, care aides also noted that a balance of knowing the resident and knowing dementia is necessary, that is, understanding that the disease state may complicate or change those known preferences. In all cases, flexibility appeared to be a key element of providing nutrition care.

Additionally, care aides noted that the work routines or overall schedule of the LTC can conflict with the personal care plan of residents, and that this is an added challenge in trying to achieve a balance in the resident’s nutrition care. For instance, a care aide may be responsible for many residents simultaneously and that could present a challenge in staying present and aware of each individual resident’s immediate care needs.

4.3.1.3 Operational Demands

Care aides described the workload as often dictating the care available, and noted that the workload is not a static principle partly due to the transient care needs of the residents with dementia and partly due to organizational situations like working through a staffing shortage. They described a type of interdepartmental competition where demands of each department

might conflict and yet care must be accomplished within the interdepartmental constraints. For example, a tension was expressed between the care staff and the kitchen staff.

*“Our kitchen runs on a clock – there is no flexibility.”
“You want to make it feel like a meal for them, not a rushed thing, you know. We have dinner from noon ‘til one. We have to be done – whether you’re done or not, your plate is getting taken.”*

To complicate matters, competition also exists intra-departmentally, amongst individual staff care providers among the same category. Care aides noted that it may be difficult to work with some, that their attitude or manner of conducting care is a consideration operating in the background.

The many residents with specific needs or demands often compete for priority and the care aides described the challenge of attending to the numerous competing interactions amongst residents while trying to achieve nutrition care, complicated by the context in which most eating takes place within LTC.

*“So in addition to that one-one-one, knowing that one person and trying to get that someone to eat, you also have all these other people around, and maybe this person’s bugging this person and this one needs his meat cut, and this one needs prompting...”
“You’re supposed to be sitting at eye level but you’re bouncing around from chair to chair so it’s disrupting them every time they’re eating and you’ve got them focused, you’ve got to bump over to somebody else. Dishes clattering, [kitchen staff] are collecting dishes or serving dishes while you’re still trying to assist – the TV’s going or another resident’s screaming for no apparent reason. It can be a madhouse.”*

4.3.1.4 Coping Strategies

Care aides identified that a large part of their workload related to nutrition care for residents with dementia involved coping, or developing strategies to compensate for lacking human resources, knowledge resources, or tools to facilitate nutrition care. Much of their time was spent in adapting to the current moment of care with the residents and responding as best they could. A

group of care aides described pretending to have coffee with a resident, and described that the socialization helped the resident to feel comfortable and stay focused on eating. Many described use of sweet foods to stimulate eating, either by providing a dessert item first, or by giving a taste of dessert first when assisting a resident to eat. Most examples of coping strategies related to increasing the amount consumed.

“If they don’t want to eat right now you try again later, try something else.”

“Well, like somebody with dementia, you can try so many different things to feed them that are not right for ... but they work, so you do it.”

“Sometimes I give them a taste of dessert first and then alternate [with other parts of the meal] and that does work.”

Frequently, care aides described a reliance on commercial nutritional supplement drinks for residents with dementia. In many cases it was described as a necessary and regular component of nutrition care for residents with dementia.

“If you feel [what the resident ate] is not sufficient, you grab a [nutritional supplement] or something else, or two desserts.”

“If you can’t get the food into them, you try a little harder with the [nutritional supplement].”

“They get [nutritional supplement] three times a day, some of them. We have people that can live a long time on [nutritional supplement].”

Coping strategies appeared to be developed out of necessity in the moment of direct care, and while they could describe why they were a necessary component of their work, care aides had a difficult time articulating how they devised a particular strategy or whether it would eventually become a normal aspect of their experiential learning.

“Actually, I don’t know how we come up with these thing, but you just do. And you pass it on and it might work only for one person ever and then it’s done, or maybe it comes back again for someone else later on.”

This constant intercession was perceived as a normal aspect of care aide work when dealing with nutrition care, and focus on the short term or immediate superseded any consideration of long-term goals or care planning. Responses to questions of how intake was tracked or nutritional status measured entirely focused on the specific meal or day, noting that if an issue seemed serious they would record it on a communication board or book at the nursing unit. The majority of communication occurred between aides informally, and many assertions of the importance of communicating amongst each other were made. Notably, they discussed involving the nurse if they felt an issue might be of importance, such as coughing or choking on foods. When asked, none of the care aides reported working with a dietitian on issues related to nutrition and residents and few were aware that a dietitian visited their LTC.

“We keep track and we’ll keep putting it on the board – I mean, if something ever goes five days in a row, you know, the nurse is obviously going to do something about it. ... they’ll have a swallowing assessment person come, which might take two weeks or four months... They do come, it just takes a while. So then you’re trying all this other stuff in the meantime.”

4.3.1.5 Operationalizing person-centered care (PCC)

PCC is a complex theoretical orientation to care that aides are asked to operationalize and multiple interpretations of PCC were demonstrated by care aides. For some, the ability of the resident to say no or refuse intake was a prime quality of PCC, while for others cueing, prompting, continued attempts to promote intake were strong considerations. All care aides demonstrated an understanding that food and drink should never be forced upon a resident, and that the approach to eating and drinking should be positive and kind. Some described a subtle negotiation with the resident to eat, or a need for the resident to be convinced that food was safe or familiar. Many care aides noted that arguments or disagreeing with a resident with dementia

over food or orientation to time and place were not effective, noting, “*you’re never going to win.*”

In many cases, care aide language demonstrated an appreciation for PCC philosophy but difficulty putting PCC into practice. For instance, care aides explained that they no longer use terms like ‘sippy cup’ or ‘bib’ and instead say ‘lidded cup’ and ‘shirt-saver’ because, “well, they’re not babies, you know.” In one case a care aide interrupted and corrected another when a term that didn’t reflect PCC philosophy was used:

CA#1: We’re pressed for time. Sometimes it can take two hours to have a meal. And there’s just too many people to feed sometimes...

CA#2: Not ‘feed’.

CA#1: ‘Assist’, sorry! I’ve been corrected many times. We’re not feeding, we’re assisting. I understand we have the philosophy, but there’s so many residents to only so many caregivers.

Central to PCC was knowledge of the individual resident, but how to use that knowledge to accomplish PCC was less clear. Care aides articulated the importance of choice and preference in foods when performing PCC, but also noted that these concepts are complicated within an institutional setting. In some cases, there is only one option available for a meal and in other cases, personalization or tailoring is not operationally feasible.

CA#1 “We have a resident who wants an egg [that is] runny. We told the kitchen staff and they said no, they’re not going to make that kind of egg.”

CA#2 “Frying them up separately is just not possible, and you do that for one... it’s not really fair at all. You can’t do that for how many people everyday, every morning. We’d never get out of the dining room.”

4.3.1.6 Perception of nutrition care

In discussing nutrition care for residents with dementia, the focus of care aides was largely on the mechanistic aspects of nutrition care, namely, ‘getting food into people’. The majority of

discussions focused on mealtimes, feeding assistance, and actions that facilitate or increase intake, particularly when a resident is resistant to eating. In one instance a care aide noted that it is important that the food at the LTC be of high quality and nourishing. In another instance a group brought up the potential for respiratory aspiration of food if a resident was force fed. There was little discussion about broader components of nutrition care such as tracking intake or monitoring for signs of dehydration or inadequate intake, even when prompted.

The psychosocial aspect of nutrition care was discussed in several of the groups. Care aides noted that eating ‘is a social thing too’, and that “[the social aspect] is almost as important as the nutrition because they never come out of rooms except to eat.” Care aides described social processes during mealtimes such as holding a resident’s hand, stroking their arms, chatting with them, singing to them, and generally interacting in a positive and social manner. However, it is noteworthy that these actions were described as methods to increase consumption of nutrients, not as an important aspect of nutrition care.

Largely, care aides purported that the primary goal and their primary role in nutrition care was to get nourishment into the person’s body. In many ways, this triumphed over PCC.

“There are no rules. Really, you’re just hoping they’ll get some nutrition in them in that day ... day by day, whatever works.”

This mechanistic focus was enhanced by their fear of the consequences of malnutrition on the residents, and fear that their care would be called into question. In one discussion, a care aide described the negotiation of eating that was undertaken instead of force-feeding a resident, then presented a real fear of consequences if they do not achieve any intake:

“But then on the other hand, then we get written up in the newspaper and everything saying that this woman lost so much weight, they’re malnourished!”

Alongside this mechanistic focus, some care aides seemed to disregard the complexity of safely and respectfully accomplishing a goal of getting nourishment into a body. Overwhelmingly, care aides described scenarios of great complexity in providing nutritional care for residents with dementia; simultaneously, assisting residents with mealtimes was spoken of as if it were a simple task. The term feeding was used often and in some cases referred to in a simplistic and somewhat derogatory manner, “Well, it doesn’t take a genius to know how to feed.”

This particular issue was illustrated by a mealtime following a focus group discussion. The care aides described their ‘feeder wall’, where they arranged residents with severe dementia in a line against a dining room wall facing outward. The care aides would then intermittently provide a spoonful of food to each resident while attending to other residents seated at the tables. It was clear that the central aim was to get nutrients into bodies.

The three theoretic categories seem to underscore and inform much of what was presented in the operational categories. That is, the mechanistic perception of nutrition care, challenge in operationalizing PCC, and development of coping strategies construct the possible or available methods for care aides to address competing care demands, develop competence to function independently via experiential learning, and balance each resident’s nutritional care needs.

4.3.2 Case scenario

In order to demonstrate the interrelationship among the thematic categories and how these coalesce, an illustrative case example concerning flexible breakfasts in LTC will now be described.

Within LTC, flexible or relaxed breakfasts have become more popular in recent years. A flexible breakfast refers to allowing residents to choose when they wake in the morning and come to breakfast, rather than requiring all residents to be ready and seated for a communal breakfast at a

prescribed and finite time. Often residents are allowed to decide the level of personal care (i.e., grooming activities such as shaving, washing, state of dressing) they choose to complete before entering the dining room for flexible breakfast. Another key aspect of flexible breakfast is the resident's choice of what they will eat and when. This may mean that options such as toast are made on demand, and other options such as hot cereal and eggs are held in warmers ready to serve. Care aides demonstrated mixed feelings about flexible breakfasts. They endorsed it on a philosophical level, noting that they agreed that residents should have the right to sleep as late as they choose. However, they described flexible breakfasts as a challenging situation in terms of care work, and an impossibility to fully realize within LTC.

When approaching the flexible breakfast, the thematic categories are seen in operation.

Experiential Learning: Care aides rely on what they have experienced in terms of scheduling of the flexible breakfast on other days when considering their attitude and approach to their workload for the morning and use this past experience to inform decisions that will be made. They use strategies that seem to have worked in managing the nutrition care at flexible breakfasts in the past.

Balancing Resident Care Needs: Care aides are aware of particular needs of each resident and this factors into decisions about the approach to the morning. For instance, they consider how long it takes a particular resident to ready him/herself in the morning, they note whether someone's medication is needed earlier and with food, they think about the number of residents who require assistance with ADLs of personal care and eating. They make implicit judgments about which of these considerations is of higher value on that given day/time.

Competing Demands: Care aides then weigh the competing demands of staff ratios to complete care tasks, assistance with ADLs including eating, medical care responsibilities, and bathing

schedules. They are also aware that though the breakfast is flexible, it is not infinite and spacing of breakfast and noon meal must be considered.

Operationalizing Person-Centered Care: Care aides then determine who they can allow the true choice of when to wake up and who they may need to wake earlier than they might prefer. They consider the decision in terms of which aspect of PCC is more critical at that moment – resident choice to sleep later or attending a breakfast where they might experience beneficial social interaction. They also make determinations of which residents will mind the most if woken, and which residents will not mind or may not be aware of choice in waking.

Coping Strategies: Knowing that not all residents can sleep as late as they like, the care aides enact processes that represent a compromise of the resident care needs and competing system demands. They may turn on lights to cue wakefulness, they may enter resident rooms and promote an appetizing breakfast, or they may simply wake a resident.

Perception of Nutrition Care: Understanding the time limitations and inadequacy of the coping mechanisms to bridge PCC and the system requirements, the focus turns to the mechanistic tasks associated with getting food and fluid into bodies rather than promotion of an enjoyable meal where choice is offered and independence is promoted. Monitoring safety, enjoyment, and tracking become secondary concerns to the challenge of ensuring each resident has achieved breakfast intake.

In this manner, the perception of nutrition care then informs their experiential learning for the next day of flexible breakfast and the cycle continues, with each turn having the potential to solidify the attitudes, beliefs, and practices as the correct way to provide nutrition care.

4.3.3 Impact of Rurality

In terms of the impact of rurality, a sub-analysis was conducted examining the rural versus urban data. Rurality presented as both a strength and a challenge in terms of nutrition care and dementia. Negative or challenging aspects included the amount of food choice available, access to specialist support, and employment challenges in recruitment/retention. In terms of food choice, care aides identified challenges in the limited menu where only one item was offered rather than two different items offered in the urban setting, and also the limited availability of food suppliers servicing the rural areas. The care aides noted that specialist services related to nutrition care such as dietitians, speech-language pathologists, occupational therapists, and behavioural consultants are less available to the rural homes, and that their visits are predetermined based on travel schedules and not necessarily responsive to resident care needs. Employment challenges described by care aides included a smaller pool of applicants for care aide positions as well as increased cost associated with training due to a policy that all healthcare workers complete a full week of orientation in the city prior to on-the-job training. In the rural setting this includes the cost of travel and accommodation for the week, and care aides described situations where after the time and expense was invested and the new hire began training as a care aide within the LTC home they identified that they did not enjoy or were not suited for care work.

The strongest positive aspect of rurality was the personal knowledge of the resident with dementia as well as their family members as this helped with PCC, and with communication with families. One attribute of rurality presented as both an asset and a challenge: independent troubleshooting by care aides. This was an asset in that care aides appeared more empowered to independently make and execute care decisions regarding nutrition for residents with dementia,

however this was also a challenge in that there was less mentoring support or facilitation that is essential for redirecting decisions that did not reflect PCC or evidence-based nutrition care practices.

4.4 Discussion

Care aides provide the majority of direct care to residents in LTC, including nutritional care, and as such are an important vocational group to understand. Their perceptions and abilities direct the manner in which nutrition care is executed, and whether it enhances or detracts from quality of life for residents, particularly for those residents with dementia.

As seen in this study, the day to day decisions regarding nutrition care are most often made at the direct interface between care aide and resident. Possibly, each nutrition care decision, from timing, context, and environment in which meals are provided, to choice and delivery of foods, represents an execution of policy and evidence. Many of these decisions may occur at the macro planning level and can be said to frame nutrition care (e.g., menu planning, dining room environment), but most occur in the immediate moment of food provision (what is offered or not offered, how it is offered, when/where it is offered) and are enacted by a resident-care aide dyad. Both resident-level and system-level information is taken into account and integrated by the care aides and resident in the decision-making process.

Dementia presents diverse and complex nutrition care needs within the LTC setting, and this is well-recognized by care aides in this study. Nutrition care takes place within a context of care that is complex and interdependent, making it difficult to consider nutrition care practices discretely (Cammer et al., 2014) and also tailor care to individual residents (Watkins et al., 2017). Certainly, the findings of this study support that nutrition care within LTC is not

composed of discrete practices, but is a dynamic context within which decisions are weighed against multiple considerations including contextual factors, resident needs, system/institutional needs, philosophies of care, and the resident themselves. A holistic examination of how nutrition care fits within this context is crucial to understanding how support is best given, or to tailor interventions that minimize rather than exacerbate the existing competing demands and challenges that care aides regularly experience.

While care aides voiced an understanding of the importance of nutrition care for residents with dementia, descriptions of how they do or potentially could achieve this were lacking. A gap existed between their expressed views of nutrition care being critical to health and a key aspect of pleasure within LTC, and their ability to describe or even imagine possible ways to accomplish good nutrition care. Perhaps this gap belies an impediment in the system: the focus on routine and schedule impedes creative problem solving. Chaudhuri et al. (2013) suggest that structural empowerment of aides via shared governance and supervisor support may be a route to improve resident care generally, and this is certainly possible with regard to nutrition care. However, as we saw in this study, care aide empowerment is not without risk; independent decision-making is only successful if the decisions are rooted in evidence. A potential for decreased quality of nutritional care exists if these strategies are not monitored and evaluated. For care aide empowerment to result in successful nutrition outcomes for residents with dementia, investment in nutrition education/training and supportive supervision would be warranted.

Care aides demonstrated limited interaction or connection to other healthcare providers, noting that their communication was largely informal and amongst themselves. They did discuss reporting concerns and issues to nursing staff or recording more formally, but a determination

was made as to when a situation was substantial enough to warrant this. It seems that for care aides, a closed system of communication exists pertaining to nutrition care and residents with dementia. The lack of collaboration or reliance on expertise from other trained providers, particularly dietitians, is a troubling finding.

Reimer and Keller's 2009 study identified four categories central to PCC for mealtimes in LTC: providing choices and preferences, supporting independence, showing respect, and promoting social interaction. Findings from this study demonstrate that PCC is indeed a complex orientation to nutrition care, and the multiple perspectives allow for many, sometimes divergent, interpretations of what constitutes PCC in a given situation. A practice that may reflect PCC philosophy for one resident or in one discrete instance may not constitute PCC for another resident or in a different circumstance. For example, when managing the needs of multiple residents with dementia, does it make more sense to remove a resident from an area if s/he is loudly singing and disrupting another resident's eating? If left in the area, social interaction is promoted, but potentially to the detriment of a resident who prefers quiet conversation or a relaxed eating environment. Or, if a resident refuses food or beverage at the time it is scheduled, how is this accommodated in the subsequent tasks of the day to ensure adequate intake?

PCC practices related to nutrition care then present a challenge for care aides as they are not predetermined and are continually renegotiated, sometimes to balance needs among residents and sometimes moment to moment intra-resident. In some instances this appeared to allow for greater flexibility and tailoring of care to the individual, but a risk exists where quality care standards are disregarded under the auspices of PCC. Simmons cautions, "... care practices that are established for staff convenience and potentially reflect substandard care quality should not be perpetuated based on the argument that the care is consistent with resident preferences."

(Simmons, 2006, pp.220). This could clearly be of risk in the case of promoting food intake and connecting with residents as care aides verbalized a strong reliance on nutritional supplements over food, particularly when rushed for time. Though a 2013 review concluded that use of nutritional supplements could increase body weight among persons with dementia, (Allen et al., 2013) these products are not meant to be a first-response strategy to enhance nutrition care for residents with dementia, and, as noted by Keller, 2016, use of nutritional supplements is not a panacea.

A core finding from this study is the ‘system-focused’ care that is enacted in terms of nutritional care, rather than person-centered care. That is, the systemic obstacles of the LTC context dictate the nutritional care provision and severely limit the ability of care aides to be flexible or tailor their care to each resident with dementia. This corresponds to findings by Pelletier (2005) who described a category of care aides as ‘technical feeders’, whose primary focus is ensuring adequate intake by residents, as opposed to those who value a more holistic approach to nutrition care.

This ‘system-focus’ may augment the perception by care aides that nutrition care is essentially equivalent to mechanistic feeding. In an exploration of the social meaning of food in LTC, Lowndes et al. noted that food is medicalized in a manner that intake of food and fluids is prioritized over all other factors such as socialization and enjoyment (Lowndes et al. 2015). This is an important consideration for LTC practice as this limited view could have unintended repercussions that impact resident quality of life, particularly within the vulnerable subset of residents who have dementia. Keller (2016) proposes that the psychosocial aspects of eating may be a higher priority consideration than intake when determining interventions that improve intake

for persons with dementia, and White (2005) advocates enhancement of the hedonic properties of food in nutritional care for persons with dementia.

Returning to Sackett's model of EBP, the care aide bears the responsibility for clinical expertise and patient/resident preference when executing nutrition care for residents with dementia. This alone is not ideal, but given the scarcity of evidence to support nutrition care practice in LTC, the risk becomes more apparent. Ad hoc decision making and anecdotal experiences may inform practice much more than is ideal. A 2014 systematic review by Liu, Cheon, and Thomas concluded that there is a limited body of evidence regarding interventions to reduce mealtime difficulties for residents in LTC and it is based on lower quality research. Similarly, a 2013 systematic review by Whear et al. showed that mealtime interventions aimed at improving behavioural outcomes of LTC residents with dementia are sparse and of low quality. The paucity of evidence-based interventions and absence of care guidelines for nutrition care of residents with dementia furthers care aide reliance on anecdotal coping strategies.

Thematic categories are presented as 'operational' or 'theoretical' in order to differentiate between those that are related to care aide decisions rooted in the context of LTC versus those that belie a more philosophical orientation to LTC care practices. That is, the categories, 'Balancing Resident Care Needs', 'Experiential Learning', and 'Operational Demands' represent nutrition care practices that arise as a direct result of the LTC context. In comparison, the categories, 'Coping Strategies', 'Operationalizing Person-Centered Care', and 'Perception of Nutrition Care' are born of care aides' attitudes and beliefs about nutrition care practices within LTC. As such, more discrete interventions that target specific behaviours could be made specific to the findings in the operational categories, while broader system changes may be best aimed at the categories in the theoretical categories.

An examination of how care aides conceptualize nutrition care provision, what they consider their role, and how it can be best achieved in the LTC setting lends insight into the sources and types of evidence that most inform nutrition care decisions at this direct care interface. Findings from this research suggest many opportunities for intervention to enhance quality of nutrition care such as enhanced practical or on-the-job training with care aides, greater coordination of nutrition care, supportive supervision, and adaptive mentoring to help support care aides in performing nutrition care practices. Interventions that address the root attitudes and beliefs surrounding nutrition care practices for residents with dementia will be critical to enhancing care aide practices.

4.5 Limitations

This study was conducted in a discrete geographic health region which may be a factor for consideration when considering transferability of findings to other LTC homes. The broad nature of the inquiry limits the specificity of recommendations and further research examining the relationships of other care providers in the process of nutrition care provision is warranted before major system-wide changes can be developed.

4.6 Conclusion

This research sheds light on the care aide's role in nutrition care for residents with dementia. Maybe the most important aspect of this inquiry is the finding that care aides perceive nutrition care for residents with dementia as equivocal to the mechanistic aspect of feeding rather than a multifactorial process that considers resident quality of life and is intrinsically linked to many operational, philosophical, and resident level factors. Further research to develop an understanding of how decisions are made in the moment of direct care provision as well as how

care aides determine what is noteworthy to formally report or record will help to determine realistic and effective strategies to enhance care.

Chapter 5: The Downstream Role of Registered Dietitians Providing Nutrition Care for Residents with Dementia in the Long-term Care Setting

5.1 Introduction

Dementia is the top chronic condition prompting relocation to long-term care (LTC) (Prince, et al., 2013) and it is estimated that between 45 - 60% of Canadian LTC residents have a diagnosis of dementia (CIHI, 2016; Wong, 2016). Persons with dementia are at higher risk for malnutrition due to both physiological and behaviour changes. Malnutrition can accelerate cognitive decline, increase risk of negative health outcomes (unwanted weight loss or gain, muscle wasting, infection, poor wound healing, pressure ulcer formation), and negatively impact quality of life (Chen et al., 2001; Mitchell, 2009; Smith & Greenwood, 2008).

Dementia has been shown to be a causal factor in unintended weight loss among LTC residents, and has been associated with increased morbidity and mortality (Salva et al., 2009; Tamura et al. 2013). Prevalence of malnutrition post-admission declines among LTC residents who do not have dementia but not among residents who have a diagnosis of dementia (Meijers et al., 2014). Poor nutritional status in LTC residents with dementia is well known and nutrition care, ranging from provision of therapeutically appropriate, high quality menus to individualized resident nutrition care plans, is crucial in preventing or addressing malnutrition and enhancing resident quality of life (Milte et al., 2017; Keller, 2016). As well, a person-centered approach is a recognized best practice in terms of nutrition care for residents with dementia (Brooker, 2007). Residents with dementia face problems with intake and nutritional status due not only due to the physical disease progression but also due to care, as staff in LTC report difficulty in food provision and feeding residents with dementia (Pasman et al., 2002). Within LTC the majority of direct care activities related to nutrition (e.g., delivery of food and beverages, assistance with eating and drinking, recording intake) are performed by care aides who have limited training in

both nutrition and dementia and rely on task-specific nutrition care (Pelletier, 2005). Care may be further challenged by a rural context. Rural LTC staff may develop coping strategies in response to reduced availability of specialists rather than seeking consultation or relying on support (Leach & Joseph, 2011), and increased hospital admissions at end of life may result from reduced capacity within rural LTC (Gessert et al., 2006).

The role for registered dietitians (RDs) in LTC is increasing (Wassink et al. 2010), however, current practice recommendations for nutrition care in LTC do not address dementia (DC, 2013). While RDs are recognized experts in nutrition care and crucial members of the interdisciplinary LTC team (Lilly & Gaudet-LeBlanc, 1992; Jurkowski, 1998; Roberts, 2011), the RD role in LTC is not clearly defined (Wassink & Chapman, 2010) and LTC practice is often devalued by RDs themselves (Lordly & Taper, 2008). Little is known with respect to the RD role specific to dementia care within the LTC context; the aim of this study is to examine the role of dietitians in providing nutrition care to residents with dementia in LTC.

5.2 Research Question

This study sought to answer the question: From the perspectives of RDs who practice in LTC, what is the role of the RD and what supports and barriers exist for RDs in providing nutrition care specific to dementia in the LTC setting. A secondary objective was to examine the influence of rurality on the RD role.

5.3 Methods

A qualitative approach informed this study. Specifically, grounded theory methodology (Charmaz, 2014) framed this research. According to Charmaz's constructivist grounded theory, participants and the researcher co-construct data through the research process.

5.3.1 Setting and Participants

This study took place within the province of Saskatchewan (SK), a geographically large prairie province in Canada (588,243 square km) with a population density of 1.9 per square km, making rural healthcare a challenge and concern (Stats Canada, 2016). In-depth interviews were undertaken with RDs from 9 of the 13 different geographic health regions in place at the time of the study. Three of the regions at the time of the study had very few LTC homes and one region was not included due to its LTC RDs undergoing reorganization. Participants were initially identified from the SK Long-term Care Action Group member list. Theoretical sampling was used where future participants were identified based on their potential ability to address an aspect of the inquiry as it developed, and to ensure a broad representation of RDs from different areas of the province and who worked under different organizational models. Interviews were digitally audio-recorded and transcribed verbatim.

Potential participants were contacted via telephone and email and invited to participate in the study. Among those who agreed to participate, a time and location were scheduled at the interviewee's convenience, often at the RD's workplace. Only 2 RDs who were contacted with an invitation to participate elected not to participate in the study. These RDs did not respond to email or telephone messages therefore their reason to not participate is unknown.

5.3.2 Data Generation

A semi-structured interview method was undertaken. A set of initial guiding questions and prompts was developed at the outset of data generation, and in keeping with the constant-comparison method germane to grounded theory method, analysis began in tandem with data generation which then informed future interview questions. Questions and prompts were

continually refined as the project progressed, as well as in response to the interview in situ. That is, a standardized script of questions was not used, and instead the interviewer guided the process and reacted to the interviewee's responses in order to form a more conversational tone to the interview.

The study was approved by the University of Saskatchewan's Behavioural Ethics Review Board (Beh 15-150). An informed consent process was included as a part of the study. A study consent form was reviewed with the researcher before each participant signed to acknowledge their consent to participate and a copy of this form was given to each participant (included in Appendix 2).

The data generation process was completed between November 2015 and March 2016. A total of 27 interviews were completed, 21 of these were conducted in-person and 6 via telephone due to inclement weather that impeded travel. Participants ranged from 23 to 56 years old (mean age 38 years), and in terms of years working in the LTC setting, the range was 6 months to 31 years (mean 11 years).

5.3.4 Analysis

Data analysis used constant comparison method, beginning with open coding of transcripts and further working with the data through focused and theoretical coding. Analysis was performed by one member of the research team (AC) and data analysis was confirmed by another (DM). Saturation was reached once the relationships between initial codes and theoretical codes were complete and the resultant parsimonious grounded theory was established. Data quality were evaluated according to Lincoln and Guba's model including credibility, dependability, confirmability, and trustworthiness (Lincoln & Guba, 1985). The quality of the resultant

grounded theory was evaluated according to Charmaz's criteria of credibility, originality, resonance, and usefulness (Charmaz, 2005).

5.4 Findings

Confirmation of findings was achieved through a presentation and discussion with a group of RDs working in LTC. The initial findings were presented at a regional meeting of RDs responsible for LTC and a discussion of the thematic categories was undertaken. The group included 11 RDs with nearly equal proportions of RDs who were participants in the study and RDs who were not participants in the study. RDs felt that the grounded theory thoroughly represented an understanding of the RD role in dementia care in the LTC setting and had no suggestions or modifications to the theory.

5.4.1 The Grounded Theory: “*The Downstream Role of RDs in Dementia Care*”

The resultant grounded theory is titled, “The Downstream Role of RDs in Dementia Care”. Generally, RDs reported not being involved in nutritional care for residents with dementia in LTC until late in the disease trajectory and not receiving consults or referrals to see residents with a primary cause identified as dementia. RDs described being regularly consulted for later-stage complications of dementia, typically dysphagia or extreme weight loss secondary to the dementia, but not being consulted for dementia earlier in the disease process, indicating a downstream role of treatment of complication rather than more upstream activities such as secondary prevention and proactive enhancement of quality of life. As well, RDs reported a large number of residents on their case-load, or a large number of facilities that they covered. Generally, the skillset and expertise of RDs was noted as misunderstood by others, with stereotypical understandings of RD responsibilities or abilities impeding work.

5.4.2 Theoretical Categories

Four interrelated categories operate in LTC that push the RD downstream in the dementia care process and also impede the abilities of RDs in advocating to increase or enhance their role in the interprofessional care of residents with dementia (Figure 5.1). These categories are ‘Relationships’, ‘Resources’, ‘Siloing’, and ‘Practice Expertise’. Each category is interrelated to the others and the interaction between the categories operates to increase the limitations experienced by the RD. The depiction of the theory is such that the categories work as unit, and are depicted as ‘waves’ that spiral, cycling through the care process and pushing the role of the RD further downstream. The RD role is positioned at the center of the theoretical model, to portray not only how the interrelated categories work upon the RD, but how the RD role is a relatively small force relative to the systemic and operational challenges. As well, the categories ‘Siloing’ and ‘Resources’ are a lighter shade to illustrate that these represent organizational and systemic issues that the individual RDs have less ability to influence, and the categories ‘Relationships’ and ‘Practice Expertise’ are a darker shade to represent that these are organizational and systemic issues that the individual RDs perceive more control over, or are areas where their effort is placed in order to cope with and combat the barriers experienced from the other categories.

The context of rural LTC provision was examined and found to further challenge the role of the RD in dementia care, with geographic and time restraints experienced as a result of the rural context further exacerbating each of the categories in the grounded theory.

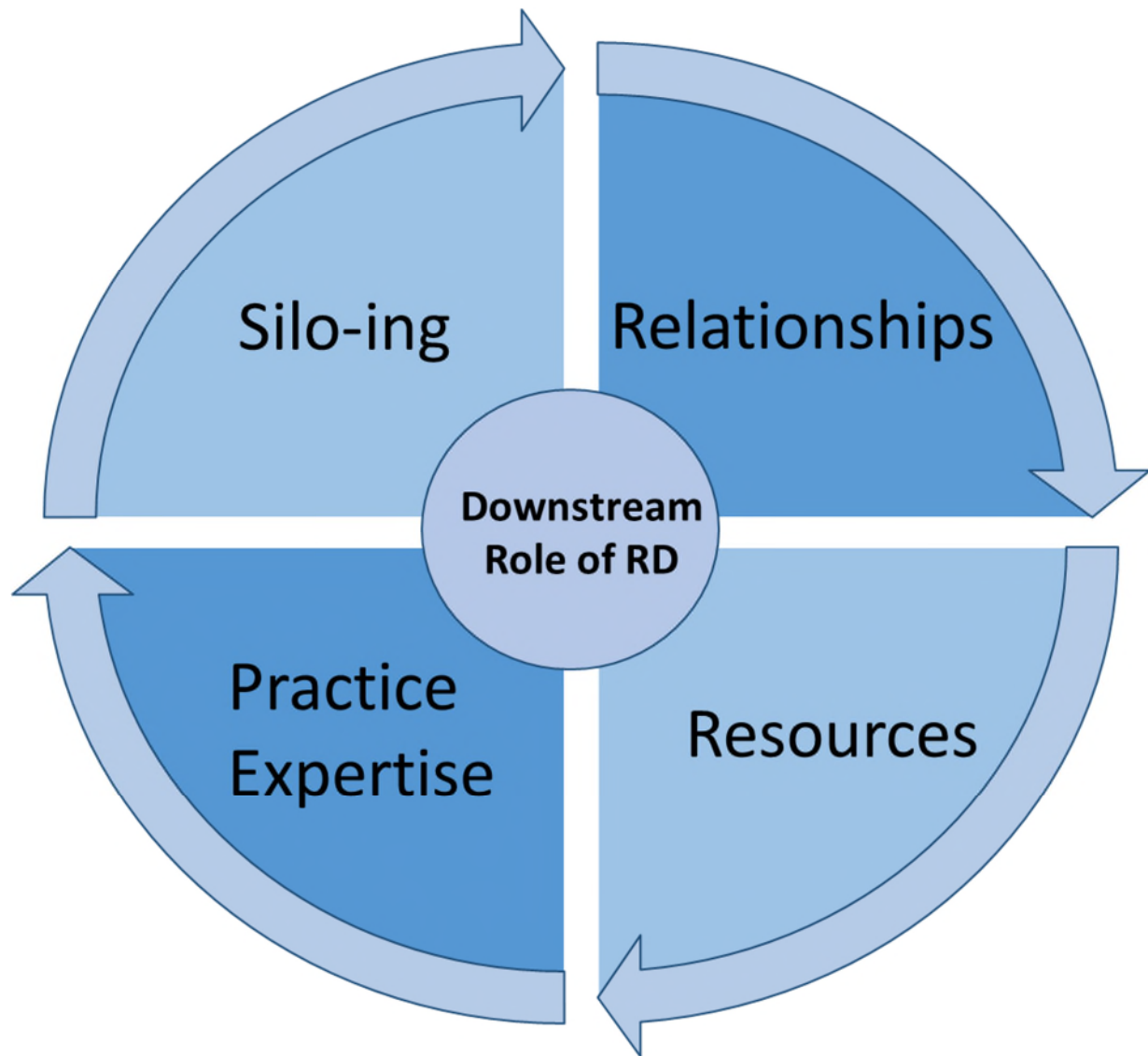


Figure 5.1: The Downstream Role of the Dietitian in Dementia Care

Arrows indicate the interconnected and reinforcing aspects of each thematic category, which then serve to push the role further downstream and the darker-shaded categories represent the areas where RDs reported investing their time and effort to mitigate the downstream role.

What follows is an in-depth description of each of the theoretical categories that comprise the grounded theory.

5.4.2.1 “Resources”

According to RDs, a central contributing factor to the RD role being pushed downstream was the scarcity of resources experienced in the LTC setting. Resources could refer to human resources such as staff time and staffing levels, or to workload factors related to resource allocation such as number of residents in a case load, or number of LTC homes in which the RD was responsible for providing care. Resources could also refer to materials such as food, supplies, training, or communication tools.

The majority of RDs were responsible for multiple LTC homes, many hundreds of residents on their caseload, and often other care responsibilities such as outpatient or acute care. RDs described having to respond to not having enough time to fulfill all care responsibilities for residents with dementia, and described frustration with the challenge of providing what they viewed to be inadequate care.

I think the biggest challenge for me is time, with having such limited hours and then also covering acute care, there isn't as much time as I'd like for my own capacity to be at each home and to give the time that's needed to really see whether your interventions are the most effective and how to streamline processes to help make things easier in nutrition care. (RD 6)

My time is too limited as well, obviously because I don't have the time to follow up on the residents as often as I would like. And it could be a few months more before I get back to them because I just don't have the time, because other pressing things come up. (RD 9)

One of the biggest challenges to me is being multi-site; I feel like I'm often at the wrong place at the wrong time. (RD14)

One RD responsible for care at three different LTC homes, each having different organizational structures and different staffing models including who she reported to, described her feelings regarding workload:

I feel like I'm pulled in a lot of different directions and that there's always that list of follow-ups and new concerns and foodservice stuff. And I wish there were more long-term care dietitians to split the workload. (RD19)

Not only did RDs describe prioritizing their own workload, but described situations where they had planned their work, but upon arrival to a LTC home, were made aware of a more urgent nutrition care matter. They described that due to inadequate resources, their time was redirected to the most urgent cases.

It trumps these other [residents with dementia] who keep falling to the wayside. ...you can't see everybody you need to see. It's unfortunate. (RD 10)

As well, RDs described having to prioritize in order to best use their expertise to impact care and health of residents with dementia. In some cases, RDs responsible for clinical care described stretching their direct resident care responsibilities to address foodservice or nursing as well; for instance, RDs worked on initiatives to improve foodservice or nursing care so that the dietetic direct care work could be implemented. Also, RDs lamented the inability to adequately educate and mentor care aides and foodservice staff in assisting residents with dementia as a result of the lack of time.

That's something we're really looking at - considering what the best approach is and where to spend our time. ...Again, the interventions that we would use are difficult given that we can't even get some of the menu pieces in place so making sure that there's someone at the queue or assisting or allowing someone finger foods isn't often an option. ... Try to suggest what you can, often not that effective. (RD16)

I'd like to be able to support the staff more, foodservice staff, care staff, nursing staff - support them more with education which I don't have time to do now. But I think if I did, a lot of issues would not be issues because they'd have a better understanding of the food they're giving to residents, why it's helping or why it's not helping, why they are giving certain things to them. It becomes better total care if they are informed on the decisions that I make on behalf of the residents. ...But I just don't have the time. Some care aides are just so rushed they just want to get the meal in and move onto the next activity that they're not stopping to assess that everything is as it should - and some of them don't realize that it could be harmful to the person that they're interacting with. But that's where the education would help. (RD 9)

A RD called her role in dementia care ‘crisis intervention’, describing that not only did she have a limited amount of time to provide direct care at each home, but other aspects of low resource allocation in LTC impact her ability to provide care. She noted that individual resident needs cannot be managed if the broader system does not allow for personalized care to be put into action, and described having to balance her time between interventions for residents with dementia and working to improve the care system to better support those interventions.

I think there needs to be a balance. There are definitely immediate needs with seeing individuals, however I think the effectiveness of an individual consult and assessment, it's only as effective as the whole picture and as the supports are in place. I may suggest diet changes for a resident but they may never be implemented. If I don't work in that big picture and help to improve the system, I'll never be effective for an individual resident. Both are extremely important and they're both needed. I think the more supportive the environment and the more the teams work well together to provide the best environment in care, probably the less I'll be needed on an individual basis. It won't be putting out fires. (RD 6)

Another RD described an awareness that care is undertaken in her absence due to the low amount of time budgeted for RD care, and the action she takes in light of this:

Although it would be great if I was consulted on everybody who needed nutritional support, I recognize I can't do that. So I try to arm the staff a little bit with some knowledge so that they can actually make some decisions and run with some things without absolutely having to be in touch with a dietitian. (RD 4)

RDs described the challenge experienced when LTC staff perform care without the ability to work with the RD regularly, or when the RD is limited in time or unable to respond in a timely fashion:

If you are waiting for someone to get an answer you're going to just 'make do' and maybe things aren't sorted out specifically on the nutrition end of things. ...You might think "why bother" and try and figure it out for yourself. (RD20)

RDs stated that because of their inability to be present at the LTC homes for an adequate amount of time, staff take on nutrition care responsibilities that would benefit from collaboration with the RD, or ‘make do’ in absence of the RD’s availability.

There isn’t a lot of availability for dietitians to the homes and as a consequence homes don’t necessarily consult because that visibility of the dietitian isn’t really there. And it’s hard to be there with limited resources. There’s a gap and missed relationship that happens. We know it’s a concern, but we’re not always aware of the situations that arise within the home. ...I think decisions are made without a dietitian involved. Whether that includes what a dietitian would have suggested or not is totally up in the air. I think decisions are made, unfortunately. (RD 2)

Because of the limited resources for dietetic care, most RDs described functioning in a consult-based model of care, but noted that this was not ideal for many reasons, including the fact that LTC staff have learned to cope with a lack of RD service.

They don’t know that that could be the role of a dietitian, or that a dietitian could help them with that situation, or they’ve been managing those situations on their own already. They probably have no clue that someone else could come in and help them with that. (RD14)

I’m constantly encouraging communication- I’ve noticed that sometimes staff will take it upon themselves to do what they need to do, change the diet, modify things, prescribe things to try and deal with the situation. They don’t often send consults to the dietitian because we’re only here once or twice a month. We need a constant presence. I think people need to know that we’re out there and can be accessed at any time, and that we will change how we do things. (RD18)

It’s one of those things where ‘out of sight, out of mind’. And often the homes almost forget that there is even a dietitian to be consulted. (RD 4)

RDs noted that it is not only the RD time that is in short-supply, but all LTC staff function in an under-resourced manner. Some found effort wasted in the absence of staff to enact the care plan they recommend, or if they are not able to ensure staff understand and are able to execute the care they prescribe.

It doesn’t matter how good the dietitian is in terms of laying out a good nutrition care plan if the staff aren’t there to be able to provide it for them, to feed them or to

encourage them to eat, or to make the specific foods that they want or only want to eat. ...And it is really sad that it's not a priority for helping these people... But there's no staffing standards for long-term care. (RD9)

I can give recommendations of what things might help improve their food intake if they've had weight loss, but the hardest part is really knowing whether they're being implemented consistently, and without being able to visit the care homes more frequently, it's really hard to know. (RD 6)

RDs described a lack of tangible materials that could support dementia care, and also lack of other expertise that could help to develop an interprofessional care model.

We don't have Occupational Therapy, we don't have Physical Therapy, or even assistants. So that makes it really difficult. We don't have access to that kind of expertise. (RD 9)

RDs also described the lack of standards in terms of ratio of RD to residents, or other care staff to resident as a detriment that contributes to the under resourcing of LTC, which in turn makes the RD role more challenging.

If you could have a baseline of this is how many staff you should have for this many residents ...that would help at least in terms of getting [residents with dementia] proper attention, and they're falling between the cracks because there's just not someone to see them. ...We're not magic, when we see [residents with dementia] and they're so far gone with a pressure ulcer or whatever it might be, it's really challenging to try and make them better, whereas if we'd seen them before it'd gone to that it probably wouldn't even affect their quality of life because you'd catch it before it got really bad. (RD 5)

5.4.2.2 “Siloing”:

RDs described the LTC setting as a challenge due to two ways in which siloing occurred within LTC context, that is, operating in a discrete and independent manner rather than holistically. The first is the way in which each LTC functioned very differently from others, with less standardization than was perceived as ideal by RDs. The second involved the division between different departments within each LTC home. Though an interprofessional model of care might be aspired to, operations at the LTC home level functioned very much in terms of discrete and

boundaried departments. RDs described challenges in providing nutrition care within this context in a variety of ways including negotiating redundancies in workload, managing different organizational models, coordinating care amongst the different departments, managing communications, and contending with hierarchies in the care staff. Because each area of care operated in a silo discrete from other areas of care, RDs reported being tasked with bridging these as an additional part of their role.

Some RDs discussed difficulties that stem from variability in the organizational models or procedures between the many LTC homes they are responsible for.

I've got 200-and-some beds but it's also five facilities that I'm visiting, and every facility is unique. The dining experiences, even where to chart, the charts are different. I just find there's a lot of lack of standards. (RD13)

Even the format of the facility can make how to provide care and who provides care and when and all of that to be, seems like I've used that word 'challenge' a lot... but just to be able to meet the resident's needs when there's probably other things that are needing to be addressed in different ways, when you look at the format of how care is even provided facility-wide. (RD25)

There's a learning curve to each home. Every long term care home is different, they have different staffing, different personalities... They also have very different processes and there's no standards in place. You're having to learn the operation again and again. I find that makes it challenging, going from facility to facility because you kind of have to learn everybody's process, and everybody has a different take on different things. (RD18)

Another RD described redundancies in communication experienced due to practicing at different LTC homes, all of which had different electronic medical record (EMR) systems. The RDs faced the challenge of learning the systems of the different EMR providers and also communicating at the LTC home, which may or may not make use of the EMR for resident care.

There is a different electronic medical record system for the XXXX than there is for XXXX and XXXX areas. ...We still chart in the EMR system, but long-term care still have their own binders [printed resident charts]. They don't use the EMR. I chart in their long-term care binder chart, but then I would also make my own note in the EMR. (RD15)

RDs noted that within each LTC home the different departments often operate in exclusion of one another, noting that nutrition care in dementia requires an interdisciplinary approach to be successful.

The whole dining enhancement [for residents with dementia] involves the whole facility in how we're interacting with the residents, how we're offering food to a resident, how we're assisting a resident and that kind of thing. It became an all-hands-on-deck approach and with that there's been a lot of push back, a lot of 'this isn't my job this is the foodservice job'. So, it's been challenging. ...There's not great communication between the interdisciplinary groups, they're working very independently. (RD18)

Another RD explained that she had invested her time in being a part of the different departments in order to solidify her role as the RD and responsible for nutrition care.

The other thing that I did was provide a lot of education sessions both for foodservice and for nursing. I think they see me as somebody that can provide education. Nurses know my name, foodservice knows my name – they know I'm the dietitian. It's just helped communication. (RD19)

Others described the lengths they go to in order to ensure that all different departments have and operate according to the same information regarding a resident with dementia, including writing out the nutrition care plan in a variety of places other than the chart, and to bridge each different department as each has a role to play in executing nutrition care for residents with dementia.

RD: Something I recently started was developing care summaries. Often we write in charts, we talk verbally, we disseminate information, but there's so much staff turnover and things can get missed. ...There have been times when my recommendations haven't been implemented, so then I'm recommending the same thing and they're not getting what they need. My initial idea to really address that was to develop a care summary for all residents I've seen at each visit and add new updates of what we're hoping to try to improve their care.

I: Your care summary, it's separate and not included in the chart?

RD: Correct. I write my summary of what I'm recommending in point form so the nurses and the care staff don't have to review every chart note I write -it's just the highlights. And I provide that to the director of care, kitchen, dietary, as well as care staff, and nursing. ...That's been quite new and I hope it'll be an effective way to communicate. (RD 6)

The separation between departments was illustrated by descriptions of operational restrictions that complicated or even impeded RDs' ability to enact simple strategies to enhance nutritional care for residents with dementia. RDs described 'push-pull' situations where tailoring a resident-centered care plan to meet needs of a resident was limited by organizational factors of the LTC home.

[In] one example, there was someone refusing to eat pretty much anything. Family was saying he really liked ice cream and that's something that we had seen success with him. ...Even just asking for that special request to give him ice cream once a day was a bit of a battle. I think they're looking at multiple [factors], 'where's a freezer that we can put it and what if everyone starts to want ice cream, it's a more costly item'. But obviously it was important for him to be getting something. It was the one thing he was eating at that time and it was a battle to even get that for him. (RD12)

The challenge of bridging care between departments was complicated for many RDs by the previously described variation in organizational practices between the different LTC homes where they practiced. Incongruences in operations represented a challenge that RDs reported independently managing. A RD described maintaining her own set of resident care files in addition to the resident chart to address this challenge.

The [screening tool] and the full assessment go into the consult section of the chart. And then normally we do our follow-up notes in the nurses' section, so that they can stay up to date with what we're doing. We found that if we just had a dietitian page ...it wasn't being seen. So now I usually [chart] in the nurses' notes. And I usually leave them a note. (RD21)

A RD who had moved from acute care practice to LTC described the difference in departmental function in LTC and the need to bridge clinical dietetics and foodservice in some cases:

I was very surprised at how much help the foodservices need or information they need if you want to make a simple diet change. They need a lot more practical examples and I'll probably get three to four questions about something that I once thought was pretty simple and straightforward. Preemptively I do it now. I will just stick around until they have all their questions answered, rather than just doing my clinical assessment and suggestion. (RD24)

RDs described power dynamics or hierarchies affecting how different departments perceive and work with each other, and the role the RD assumes in supporting different departments to enact quality nutrition care.

I think there's also a bit of a power struggle that tends to happen sometimes - that hierarchy that happens within a home in terms of the foodservice staff being lower to care staff and RNs etcetera. There's been many times when I've had a call from the foodservice lead who's identified something that shouldn't be happening and asking me to provide some sort of evidence or background to help them get their message across, because otherwise they aren't really listened to. ...And it really depends on the home and the relationships in the home as well. (RD 2)

The authority of the RD was also brought up as a challenge in that RDs make suggestions to improve work practices and enhance menus and devise nutrition care plans, but they do not supervise the staff who translate the plans into action, and are oftentimes not even a member of the department responsible to put the plans into action.

I would go in and do these audits at the homes and then I would leave them with a list of recommendations. But whether they did it or whether they didn't, it's really hard to say. (RD 1)

[Instructing staff who don't report to me is hard] - especially because a lot of them are still new faces to me. I know I will specifically go to certain people to say my recommendations because I know them. But then what if they're not the staff that is working with the resident that day? So that is a big challenge. That's why I do like working with the Resident Care Coordinator a lot because she knows the staff really well and she really values my recommendations so she will enforce – sounds strict [laughs] – but she will educate the staff on “these are the dietitian's recommendations, please assist this resident in at mealtimes at all time. (RD 8)

RDs described the impact of this being exacerbated by the infrequency of their time spent in LTC, and inability to encourage care practices to be implemented for residents with dementia. A RD described the frustration of trying to discourage a poor practice regarding improper meal assistance for residents with dementia, and the limitations of trying to create change.

Every time I'm there and I see that, I provide education. But when you're only out there once a month that's hard to enforce those. ...Because once you leave the facility they

just pretend like you weren't there and go back to what they were doing, which is unfortunate. (RD10)

5.4.2.3 “Relationships”:

In the face of challenging workloads and lack of operational standards or uniform systems and practices, RDs described a high reliance on fostering good relationships with other care staff in addition to the family members and residents with dementia. Fostering collegial working relationships at the level of the whole LTC home, each department, interprofessionally, and with residents themselves was described as essential to enact nutrition care for residents with dementia.

Many RDs described relying on other health care providers in order to perform resident-centered care for residents with dementia due in part to the nature of dementing illnesses and also to the time-restraints experienced in their positions. RDs noted the importance of consulting with residents' family members and all members of the care team.

I think it's more about understanding that they have dementia and potentially you're not going to necessarily get a lot of information from them. You need to go to the family about what this person liked, what they are used to. ...That's our job, to make sure they're eating and that they are enjoying what they're eating. Usually it takes a little more digging to get those answers, versus someone who doesn't have dementia. (RD17)

I suppose one of the biggest challenges is [residents' with dementia] inability to really communicate with you. It takes a lot of time and there's a bit of guess work that happens. You're also relying on family for interpretation or for staff who know them better. (RD27)

One of the challenges is that I don't know them as much as the other care staff do. I'm in charge of 200 people and they're in charge of six ... they know those people way better than I do. They know if they're having a good day or a bad day, if this is common or uncommon. I find that a big challenge and that's where teamwork and relying on them is huge. (RD14)

RDs described relationships as a necessity in light of the fact that their time is in high demand, and as a way to assuage the low amount of time they could devote at each home. As well, they

noted that they are one care provider among many, and all bring different aspects of the care forward; care for persons with dementia is strengthened by integration of the many perspectives.

I do think that building rapport is the biggest most important step that you can do, especially going into a new home and that's what I'll be trying to do when I gain four more sites. It's easier for people to implement your recommendations if they know who you are, and they know what you do, and you have a good relationship with them. ...I know that the care aides and the nurses do know the residents the best. They're the ones that are with them every day so I think there is a little bit of a struggle when somebody new comes in and says, 'this is how we could best provide the resident's care'. They might have a different idea of what best care for the resident is. But once you establish that rapport with the staff and you build a good relationship with them, they know that you really care about the residents too, and you know what you're doing, then they'll value your recommendations more. (RD 8)

I think when you're working with people who have dementia it's really important to take the time to develop a relationship with that person and to spend time with them. ...But sometimes I just feel like I don't have that luxury of spending days with one person, because there are just so many people to see. So I really do rely on the staff that do work with them very closely every day to teach me about this resident and their families as well. (RD 1)

RDs described the importance of finding key people to build relationships with in order to gain trustworthy information and rely upon at each LTC home, and they detailed that the particular person or position can vary from home to home. That is, the position may not define the importance of the relationship, the relationship itself may define its importance, and often it is someone who has an interest or investment in nutrition.

I work with the clinical leads in some of the homes and other homes I'm working really closely with a foodservice manager. It seems at each home there's someone that can really help you out, and it varies; sometimes it's aides, sometimes it's a foodservice manager, sometimes it's a nurse that's particularly interested in nutrition, or even a cook. ...We really rely on them to help us because we're in there so infrequently. (RD13)

As well as relationships being key to eliciting information critical to developing person-centered care plans for persons with dementia, RDs also discussed the importance of good collegial relationships to have their care plans followed by care aides.

I've done education sessions on feeding and helping and on the dining environment. ...I try to be visible on the floor so that they know who I am, they know what I do... You've got [to have] that buy-in so that they will refer to you, when they may notice things like alert you to that to change, or respect your recommendations when you're not around. And it definitely is not something that happens overnight, and I think it's also earned. I don't think as a dietitian, you can just roll up there and make your recommendations - I think it takes time, and that buy-in from them is invaluable. (RD14)

You have to be in it long enough to build up those relationships, so that there's that trust level there and also that you can educate on what you do...And I know if I'm on the unit and I have a question about a resident, I know the people to go to get an accurate answer. And I know the people that I don't want to bother asking, because I won't get an answer. (RD17)

I feel like I've learned very quickly that I need to tread lightly... I always have to remind people 'we're both just wanting to support the resident, we want the same thing here, it's not me against you.' ...I need to have a good relationship with them because they need to do the recommendations that I'm giving out. I can't be there to make sure it's happening every day. They're a huge part of it. If they aren't on board then it's not going to happen. (RD 1)

I'm just one of many as part of the team ...and the more that teams work together, the better it is for each resident, but some are a little bit easier to develop that rapport and communication with. (RD 6)

As well, RDs noted that once good relationships with other departments and staff have been established, it is much easier to perform within their role. One RD spoke about the challenge of making a food fortification change to menus within LTC, and credited her strong relationships for helping her to manage through the 'push-back' of that change.

[It is] very difficult to implement, I can see that. You know there is a healthy respect when you've worked together for a lot more years and they just trust your knowledge. You have that give and take, you trust them. You have to build rapport a lot quicker when you are a consultant, and so it does take... It's a bit of a knack. But I think I've had the benefit of being here for so many years that I can actually just rely on that relationship that has been built. It didn't come easily. (RD27)

Some RDs spoke to the aspect of relationships being even more critical given the very nature of the LTC setting and clientele, in that the LTC home is not solely a healthcare institution but also a home for residents.

I get to develop a relationship with my clients and their families. To me it's a family here, and it's a family with a nursing staff as well. And it takes a lot of years to get to that point, but it's a community here. The relationships that I get from working in long-term care - which you just don't get in any other dietitian setting. That's actually my favorite thing with my people. (RD17)

I will make sure that I do sit down with the kitchen staff and we're so small in most of my sites that it's very much an intimate conversation, and most of the time these people have been working around and know these individuals longer than I've had the privilege to know them. And they really, really care. ...And to get the whole picture you need everyone. (RD26)

5.4.2.4 “Practice Expertise”:

For the most part, RDs reported having limited formal training in dementia care and noted that learning on the job was typical, via training webinars or from other experienced RD colleagues and other experienced care providers. RDs also reported not feeling like they possessed specialty expertise in providing nutrition care for residents with dementia. Despite this, they adeptly outlined high quality, person-centered nutrition care for residents with dementia in LTC, recognizing the varied nature of dementing diseases and nutritional ramifications of the diseases.

I think when you're working with people who have dementia it's really important to take the time to develop a relationship with that person and to spend time with them. ...I have found different strategies of working with people who have dementia, such as trying to focus on finger foods, serving them right when they're seated at the dinner table, serving brightly coloured things, varying textures if they are able to have different textures, providing opportunities to eat multiple times throughout the day - I try to help staff with those types of strategies. (RD 1)

I wouldn't say I'm an expert on this area. I think there's a lot to learn in the area, but I think the nutrition care is really important for those with dementia because they can lose their connection to food in some ways. ...I think there's a huge spectrum of things that might be impacted with dementia. It definitely puts them at a higher risk of nutrition concerns for sure. ...It's very varied. (RD 6)

I find a lot of the things that we do with other clients don't always work. ...You have to be more creative. (RD13)

Trying to like help them eat in a dignified way and finding things they will eat, and things that are still healthy that you can convince them to eat. ...To maintain their

physical health, maintain their weight, maintain their health, prevent falls. ...The goal is to improve their quality of life, to be as healthy as they possibly can be ... to make the situation as best as it can be. (RD14)

RDs described ways they have developed their practice expertise in dementia to better care for residents with dementia in LTC typically via adapting standard dietetic practices to accommodate challenges encountered with dementia, or by altering goals of care to better suit the type and level of impairment.

We recognize that folks with dementia have as much right and ability to express their preferences, just not might in the traditional way we're used to...[We need to] engage with them and somehow see the ability to identify a preference in a non-traditional way. I think we're looking at strategies related to that to try and find ways to connect with people who may have dementia and that still have ability to make decisions and have a voice in our care. (RD11)

I want to make sure that they're in a safe eating environment, that they're getting the attention they need. ...The overall goal as dietitians is to marry food for enjoyment and quality of life and food for nutrition and nutrition support. ...and then of course ultimately making sure that they don't put themselves at risk for malnourishment or choking as well. (RD26)

Depending on the stage of dementia ...their needs change from the average resident whether it being increased energy needs because of activity or agitation that they burn more calories, the whole small frequent meal thing that might help them because they can't sit a long time and focus on one thing. ...I think the parameters that you're going to look at will be the same: energy needs, reviewing your lab data, looking at those types of things, [but] the strategies to provide the nutrition to them might be different. (RD22)

RDs discussed the breadth of their practice area, and the challenge in specializing in any one area of nutrition care, particularly dementia care, given the demands on their time and practice responsibilities. They also described collaboration amongst colleagues practicing in LTC and relying on one another's knowledge and expertise.

Finding the time and having the capacity to really delve deeper and do that training when you have so many residents to cover, you just don't necessarily have the time to take the office time to do the education. ...I think this is a really inspiring area. There's a really big role for dietitians in this area. I think that the more we can work as a team amongst dietitians, I think the easier or better it will be. (RD 6)

I: How did you learn about dementia?

P: Just years of being here, mentored by some great dietitians. (RD 7)

RDs noted that their own understanding of dementia was perhaps limited prior to working in LTC, and some described misconceptions about residents with dementia that were challenged once they became LTC RDs. Others noted that organization-wide, dementia is not well-addressed and that RDs have a role to play in breaking stereotypes or poor patterns of care provision for residents with dementia.

*I originally thought that it didn't matter if you had dementia or not. ...But what I found [from] going into the long-term care facilities, dementia seems to be an excuse for everything. That the person who has Alzheimer's or dementia can't tell you what they want, they can't communicate with you, they're always going to have troubles eating and drinking because they often forget what they're doing or they don't know how to ask. So we need to assist them, we need to do all of these things. [I realized] 'boy, facilities tend to use dementia and Alzheimer's as a reason why we can't do anything, why we can't offer choice, or why we can't change up our meal service- because we can't, there's nothing we can do to help them.' It's all over the literature that people with dementia **can** make decisions and it's a stereotype that we need to move away from. (RD17)*

RDS also described the need to use their practice expertise in order to influence other staff to appreciate the importance of nutrition care for residents with dementia and to increase the person-centeredness of nutrition care within LTC.

Sometimes when someone has dementia [staff] lose sight of the person that they are, the person they were. ...It's just the idea [to] just get some nutrition in them somehow, whichever way, not necessarily focusing on quality of life or best practices for things. (RD12)

I believe [staff] think [nutrition] is important. ...But some of the things that I've seen would also lead me to believe that they don't think nutrition is that important. It's just food going into your mouth and it's just something that we do three times a day, that doesn't really require a lot of time; let's just get it done so we can continue to move on. ...I think nutrition is one of the afterthoughts and people don't see it as hugely important. They don't see it as a social experience or any other sort of experiences, just something that we do. ...We have to change the culture. We have to bring it back to the resident, we need to deinstitutionalize our long-term care homes and we need to take those few extra minutes to really get to the bottom of what do they need and how

can we help them. ...We're not taking the time; we're just trying to get through our day, we're very task focused. (RD18)

A general lack of understanding of the practice expertise of RDs by all staff in LTC was expressed by RDs. They noted that this lack of understanding led to referrals very late in the stage of dementia at a point where their expertise was not as useful, or a failure to involve the RD in care planning that could benefit residents with dementia.

People don't know the role that [RDs] can play, or are not sure to the extent of which. ...It's the unawareness factor – not knowing our complete role. I think that people are very familiar with how we manage weight loss and malnourishment and all of our roles in reactive measures but not our roles in proactive measures. (RD26)

I: Why do you think dietitians aren't consulted for dementia?

RD: I think that it's because a lot of people don't know what dietitians do. I would love for there to be more education for staff who work in long-term care to say, 'hey, I'm a dietitian, this is what I do, these are all the issues that I can help the residents with, if you notice any of these please let me know.' ...I do think that there needs to be a lot more education for staff around, these are the issues that people have when they have dementia and this is how a dietitian can improve their care. (RD 8)

5.4.3 Impact of Rurality

Only 4 of the study participants worked solely in an urban setting; it was far more typical for RDs to have a mixed practice of urban and rural LTC, or to practice in a solely rural context, but to have responsibility for community, outpatient or acute care dietetics as well. The rural context further exacerbated the issues described by RDs that pushed their role further downstream. RDs spoke to the scenarios experienced due to rurality, typically additional challenges in providing care due to geographic distance, including inability to establish a regular presence in LTC homes or increased strain developing relationships that enable care. The ratio of RD time to LTC resident caseload was even lower in rural areas, and was then exacerbated by the necessary travel time between LTC homes.

Specifically in our health region... you can travel up to 2 and a half hours one way, so we're trying to implement other factors, looking at telehealth and doing things by phone if we can. Definitely trying to be in the home with the resident and with the staff members, but that's a big challenge because there and back, that's five hours of

travelling. We only have 2.1 FTEs of dietitian time and almost 3000 residents, it's a really big discrepancy. I would say that the geography is a big challenge in our province. (RD 3)

Just with driving two and a half hours - if you only work an eight-hour day, that's five hours, then you're left with three hours to see people. (RD10)

Challenge is travel, especially in the winter sometimes. This winter hasn't been too bad. I think I've only missed maybe- or had to rebook a day or two this winter. ...But besides that sometimes services you can get out here can be a challenge. (RD21)

Just seems so unfortunate that precious time is spent travelling, but you have no choice in Saskatchewan where we're hours apart from places. (RD5)

One RD who practiced in an urban setting made a comment about the dietetic practice in rural LTC based on her experiences in traveling to rural LTC homes to help train RDs in the practice area, or to assist with challenging cases. She was able to identify both challenges and benefits that RDs experience due to the rural context.

I think that I'm really lucky based on where I work [urban LTC]. And I've had little glimpses of it going out into rural - there isn't as much support out in rural. I'm lucky that I work at [urban LTC home] where we have music therapy, rec therapy, pharmacist, OT, PT, some limited access to SLP. When you're out in rural, you just don't have that. ...On the flip side of all that support, there's a lot of red tape. If we want to get a new menu item we have to talk to the procurement manager, he's going find the right bid, and we have to wait for the bid to come in, and then we have to make sure it's not a special order item. And so it's a long process. Whereas if you are in rural, well guess what? you tell the head cook, she orders it in, it comes in. So there's pros and cons to having that support, that you get a little bit more red tape in trying to make changes happen. (RD17)

Another RD described the balance of positive and negative attributes of rural LTC:

I think one of the really positive things about rural sites is that I felt they are much more home-like, less institutional because a lot of the people that lived there were from those communities, they knew them before they had dementia, so I felt like it was a lot more caring environment in some ways. I really like that about a lot of rural sites - feels more like of a home. What's more challenging is that they tend to have less services so it's a lot harder for us to pop up for a quick consult. If it's two hours away - that's a limitation. (RD16)

As well, RDs practicing in solely rural locations were predominantly community RDs who had recently been assigned responsibility for LTC residents in addition to their community and

outpatient RD responsibilities. Not only tasked with geographic distance, travel burdens, and low proportion of RD to resident caseload, these RDs spoke of struggling to balance the very diverse job demands in terms of practice responsibilities.

The community dietitians in the rural areas, they have more diverse job duties in that they're seeing outpatients often in the local hospital. Let's just say long-term care is the first thing to fall off the table. (RD 4)

[Rural Community RDs responsible for LTC] have been very honest about being pulled between their outpatient and their chronic disease work. It's very much out of their hands how much time they get in long-term care. And it's because of the demands throughout the whole health system, but they've had less and less and less time over the years. ...In a community dietitian's role they report into chronic disease management. I think that erosion was maybe a natural progression just because of where the focus would be. (RD 3)

It's purely consults. Because I also do home care, I also do acute care, and the biggest chunk of my workload is actually in chronic disease management, I can't say I'm trying to stimulate referrals [for residents with dementia in LTC] because I just can barely - like you're just trying to get done what you can get done. ...As the long-term care referrals come in, you just try to identify those that are really high-risk and I'll try to do those right away, and often remotely. We'll get things started remotely because I've got about a 90-minute radius to some of my sites. (RD13)

5.5 Discussion

This study adds to the growing body of literature examining nutrition and dementia via a thorough examination of the role RDs play in dementia care within the LTC setting. We used an evidence-based practice lens to generate a grounded theory explaining the role of the RD in dementia care in the LTC setting, and demonstrates factors influencing the RD role.

As seen in this study, the role of the RD in care of residents with dementia in the LTC setting was not functioning in an upstream or proactive manner to preserve function, prevent complications, and enhance quality of life. A common characteristic of dementing diseases is their chronic, progressive decline. As such, intervention earlier along the disease trajectory may

allow more benefit to be experienced. Keller et al. (2006) demonstrated that increased RD time in LTC was beneficial to resident health and was effective in preventing weightloss (Keller et al., 2006). Failing to intervene with nutrition care in earlier stages of dementia can lead to increased morbidity (Brook, 2014). However, dementia is not a disease with a predictable progression for all, and a tailored approach is needed for each particular resident and their unique disease experience; Prince et al. summarized that not all those who have dementia will benefit from all nutrition interventions such as supplementation, food fortification, or strategies to address behavioural symptoms (Prince et al. 2014). Having said this, Gaskill et al. asserted that many of the contributors to poor quality of life in LTC are related to nutrition and are preventable (Gaskill et al., 2008). As such, residents with dementia require tailored nutrition care plans that honour their individuality and personhood as well as their physiological needs.

In addition to physical health aspects of dementia, RDs also spoke frequently about non-physical attributes of health such as quality of life, respect, and dignity. RDs were well versed in person-centered care and noted where challenges impeded their ability to practice in a truly person-centered manner. RDs asserted that a culture change is needed in order to realize the benefits of interprofessional person-centered care. A review by Dominguez and Barbagallo (2017) criticized the scarcity of person-centered care measures or determinants included in studies of nutrition and LTC residents, noting that it is an evident need given that person-centered care approaches have been shown to increase protein and energy intake in LTC residents at risk of malnutrition. The authors also note that RDs are a valuable member of the multidisciplinary teams necessary to prevent and treat malnutrition (Dominguez & Barbagallo, 2017). Similarly, Gaskill et al. call for a multidisciplinary approach to nutrition care in LTC settings where “staff education, support

and adequate time allowance for the provision of daily care” are prioritized (Gaskill et al., 2008, p. 193).

A recent study by Murphy et al. (2017) found that person-centered care was the defining feature of good nutritional care within LTC settings, echoing the research done by Reimer and Keller (2009) who found that person-centered care was the cornerstone of nutritional care at mealtimes in LTC, but also noted that achievement of this was often limited by inadequate staffing levels. RDs made observations about the organizational context of LTC, noting that the current organizational structures, schedules, and fragmented approach to care impedes nutrition care for those with dementia (Murphy, 2017). RDs were able to identify work factors that force task-focused care provision, not only on their part, but also by other members of the care team such as nurses and care aides. This single-mindedness of tasks has been noted by others such as Pelletier (2005) who noted that nutrition care by care aides is often focused on rote feeding (Pelletier, 2005). In a recent study of RDs practicing in LTC, RDs demonstrated that their role was to push beyond task-focused nutrition care and move toward resident-focused care that addressed the purpose of nutrition care (Wassink & Chapman, 2010).

The RDs in this study were able to identify many opportunities to better use their expertise and body of knowledge to improve dementia care in a more upstream manner, but were limited in their ability due to lack of control, lack of authority, and the pressures of balancing their multiple and varied job responsibilities. Interdisciplinary approaches to care are highly valued in the LTC context, and dietitians are valuable members of multidisciplinary care teams to treat dementia (Jurkowski, 1998; Bennett et al., 2014). RDs in this study noted that relationships were a key factor in enabling their work to be operationalized, and they valued the interdisciplinary team model of care provision as the best approach to providing care for residents with dementia in

order to capitalize on the skillsets and vantages of each member of the care team. Similarly, in a 2010 study of RDs practicing in LTC, Wassink and Chapman found that RDs valued the team approach to care and prized cooperation and collaboration within a care team above task-specific duties (Wassink & Chapman, 2010). The fragmented approach to care as evidenced by different departments operating independent of one another was a direct challenge to realizing the benefits of interprofessional team care in the current study.

RDs identified that their role in LTC was limited due to many factors beyond their control, including resource allocation and caseload. The scarcity of human and material resources in LTC were seen as significant barriers to achieving good nutrition care for residents with dementia; RDs noted that care plans were hindered by the reality of what could be achieved with the available staff, staff time, and supplies. RDs described determining what was feasible on their part and on the part of the organization and the staff as a consideration when developing nutrition care plans. This consideration is not without merit; the need for staff to execute nutrition care plans is key, and the lack of staff may increase risk of malnutrition. Meijers et al. found that the care dependency experienced by LTC resident with dementia is a confounding factor in the relationship between dementia and malnutrition; that is, the dependency on others for care in activities of daily living increases the risk for malnutrition that residents with dementia already experience (Meijers et al., 2014). In a 2017 meta-analysis of the multiple domain nature of malnutrition in older adults, Cereda et al. (2016) found that the prevalence of malnutrition is higher among LTC residents with dementia than LTC residents without dementia, and stated that LTC resident dependency is strongly related to increased risk of malnutrition. That is, as the LTC resident's level of dependency increases, so too does their risk for becoming malnourished (Cereda et al., 2016). Nell et al. found that care staff support in terms of meal assistance,

prompting, and interaction with residents with dementia was key to ensuring good nutritional care for residents with dementia in LTC (Nell et al., 2016).

Workload was a challenge in that RDs practicing in LTC had a very large resident caseload, and this was complicated by the fact that RDs typically provided care at multiple LTC homes.

Dementia was only one of a multitude of conditions the RDs were responsible for understanding and treating, and RDs uniformly reported restrictions on their time as a major barrier to achieving quality nutrition care for residents with dementia in LTC. A 2003 study by Keller et al. demonstrated that increased RD time allocation in LTC could positively impact resident nutritional outcomes (Keller et al., 2003). Inadequate staffing levels have been implicated in malnutrition in LTC context, and have been characterized as a feature of reduced quality of care for LTC residents (Woo, 2005).

A feature that further impacted care provision for residents with dementia was the broad scope of not only the LTC role, but the fact that many of the RDs were responsible for multiple and different care roles outside of LTC, such as chronic disease management, acute care, and community nutrition practice. Often the responsibility for LTC service was added onto an already stretched caseload. Complicating this workload is an inefficient use of RD skillset and ability, due in part to the limited participation in interdisciplinary care teams, but also partly due to a lack of awareness of what RDs are able to contribute to care of persons with dementia, or stereotypical understandings of the RD profession by other staff. In a seminal paper on the role of dietitians in geriatric care, Lilly and Gaudet-LeBlanc posit that RDs are positioned to be leaders in the LTC setting, and define dietetic practice in LTC as spanning three major areas that encompass distinct responsibilities: 1) Food Availability: menu planning, recipe development; 2) Food Consumption: empowering the resident, optimizing dining experience, marketing good

nutrition, evaluation of eating skills, eating rehabilitation; and 3) Biological Utilization of Food: nutritional assessment, nutrition care plan (Lilly & Gaudet-Blanc, 1992).

This lack of understanding of the RD abilities in LTC is not limited to allied providers and other staff within the LTC setting. A 2008 study of dietitians found that the role of RDs in geriatric LTC practice is undervalued by the profession of dietetics itself (Lordly & Taper, 2008). Among the participants studied, the authors found less importance placed on the interpersonal skills needed for dietetic practice in LTC and a devaluing of the holistic approach to care that focuses on resident quality of life (Lordly & Taper, 2008). This may speak to an overarching misunderstanding of the importance of quality of life in nutrition care or presence of a hierarchy where acute care practice is seen to be more nutritionally scientific and therefore more highly valued. Nevertheless, if the dietetic profession generally undervalue the role of RDs in LTC practice, perhaps it is unsurprising that RDs are similarly undervalued or misunderstood by other members of the LTC team, particularly with regard to care of residents with dementia. Current work on creating geriatric interprofessional team training experiences for healthcare students may help to combat the misunderstandings about the role of the RD, and may help to raise the profile of geriatric care as well (Ford, et al., 2013).

The impact of rural practice locations served to exacerbate challenges RDs experience in their role providing care to residents in LTC. Though some positives were identified that the RDs attributed to the rural location, these were minimal in comparison to the barriers that the rural context overlaid on an already challenging role. The downstream nature of the RD role seemed to be pushed even further downstream due to the geographic distances, travel burdens, lack of other allied providers to consult with, and typically broader dietetic practice experienced in rural areas.

Though the role of the RD in dementia care within the LTC setting was more downstream than would be ideal for dietetic practice, RDs seemed hopeful, noting that the amount of time they had or amount of services available had improved in recent years. The RDs seemed well-prepared to provide nutrition care to residents with dementia, focusing on a person-centered holistic approach that valued respect, dignity and quality of life, and supporting others on the care team to undertake or modify practices to better achieve these outcomes as well. The need to balance biological nutritional benefits with quality of life nutritional benefits is key to nutrition care (Milte et al., 2017) and RDs are well positioned to provide this holistic, person-centered care (Douglas, 2015). As Lilly and Gaudet-Blanc stated, “meeting nutritional requirements is not an end in itself, but a means of improving or maintaining an individual’s quality of life” (Lilly & Gaudet-Blanc, 1992, p. 197).

5.6 Limitations

This research was conducted in one province in Canada and, as such, the findings may not be transferable outside of these boundaries. Theoretical sampling of participants from different geographic regions of the province as well as selection of rural and urban practicing RDs was done in effort to mitigate this.

5.7 Implications for Practice

Dementia presents diverse and complex nutrition care needs within the LTC context, which is well recognized by RDs practicing in the LTC setting. Expertise and confidence in dementia care is needed. RDs recognize that a person-centered care approach is required to provide adequate nutrition care for LTC residents with dementia. Advocating to be part of the interdisciplinary care team in a more upstream manner is required but limited in many ways due to time

constraints and the breadth of the RD role in many cases. Nutrition care for LTC residents with dementia could be enhanced through RD involvement earlier in the trajectory of the disease process.

Chapter 6: Umbrella Review of Nutrition Care for Residents with Dementia in Long-Term Care Homes

6.1 Introduction

Dementia refers to a group of chronic, progressive, incurable neurological diseases united in cognitive and functional decline. According to Statistics Canada, the prevalence of diagnosed dementia among residents living in Canadian long-term care homes (LTC), also referred to as nursing homes, geriatric care institutions, or aged care facilities, is estimated at 45 - 60% (CIHI, 2013; Wong et al., 2016). Care for these residents is of utmost importance and it is well established that dementia is associated with increased risk of poor nutrition, eating problems, weight loss, and malnutrition (Morris & Volicer, 2001; Mitchell et al., 2009; Tamura et al., 2013). In recent years, there has been increased recognition of nutrition care as a crucial element of not only resident physical health but also quality of life (Bostrom, 2011; Murphy et al, 2017). Of particular interest is the evidence base to support nutrition care practices within the LTC setting, and interventions aimed at improving nutrition related health outcomes for residents with dementia within the LTC setting.

Nutrition care is an important consideration for LTC residents with dementia who are at increased risk for malnutrition and experience impairment in eating ability (Keller, 2016; Mitchell et al., 2009; Smith, 2011). Eating and drinking remain a source of pleasure even for those with severe dementia (Pivi et al., 2012) and interventions that increase enjoyment of food and eating will also increase general well-being and quality of life (Manthorpe & Watson, 2003). As well, interventions that enhance nutrition care for residents with dementia may have the power to enhance overall quality of life in addition to nutritional health, simply by increasing the socialization and personal contact aspects of nutrition care (Bostrom, 2011; Keller, 2016; Smith,

2011). White (2005) summarized nutrition interventions stating that the interventions that increased hedonic reward appear to be significantly beneficial to those with Alzheimer Disease who are at risk nutritionally.

Within LTC, the much of the direct care responsibilities lies with care aides, also known as personal support workers, continuing care assistants, and nursing aides/assistants. However, it is the registered dietitian (RD) who provides specialized nutrition care within LTC (Roberts, 2011; DC, 2013). Nutrition care encompasses a wide range of goals within LTC that support resident health. These include proper assessment of nutritional need, provision of safe, appetizing food that is culturally appropriate and fulfills nutritional requirements, therapeutically sound food, adequate assistance that promotes independence and function, and an environment that enables fulfillment of intake and enjoyment of food (DC, 2013). Accompanying this broad range of goals are the wide variety of actions to achieve them, complicated by a diversity of activities regarding the LTC context including legislation, staffing models, and mix of residents. The body of evidence examining potential improvements in resident outcomes related to nutrition care has increased substantially in past decades and with this is an increased number of narrative, scoping, and systematic reviews addressing various aspects of nutrition care. With that in mind, an umbrella review was conducted to ascertain the current evidence base and determine gaps or directions for future research.

6.2 Research Objective

The aim of this umbrella review was to comprehensively search the peer-reviewed literature and to ascertain from systematic reviews the current evidence-based practices recommended to support or enhance nutritional care of residents with dementia residing in LTC.

More specifically, the review focused on the following questions:

1. What is reported in peer-reviewed systematic reviews regarding nutrition care for residents with dementia in the LTC setting?
2. Is consistency observed in nutrition care interventions and outcomes considered?
3. Within this body of literature, what recommendations are made related to nutrition care provision for residents with dementia by either care aides or registered dietitians?

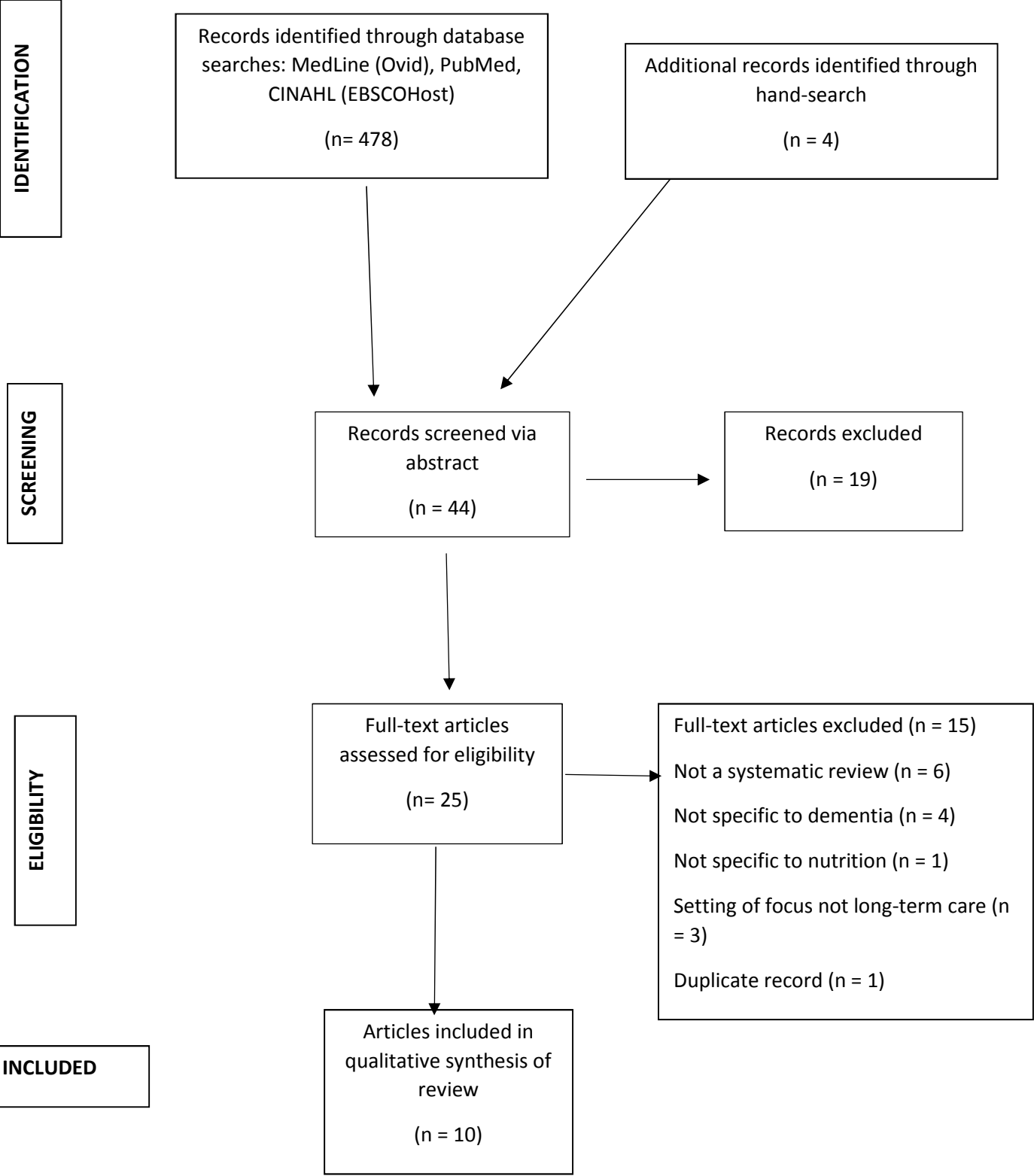
6.3 Methods

An umbrella review process was undertaken to compile and examine the state of the current literature regarding nutrition and dementia care, specifically compiling what is known and what gaps remain in relation to the research objectives (Grant & Booth, 2009; Liberati et al., 2009). A search of major research databases was conducted to identify potentially relevant publications for review. The databases used included MedLine (Ovid MEDLINE), PubMed, and CINAHL (EBSCO Host). A combination of MeSH terms and keyword search terms was used for search terms. Search terms addressed four categories: Dementia, Long term care, nutrition, and reviews. The MESH and keyword search terms used to address each category and a sample search is appended (Appendix 3).

The research objectives were used to determine inclusion and exclusion criteria for this review. Inclusion criteria for this review were: peer-reviewed publications written in English, published from 2000 to November 2017, including all search terms. Exclusion criteria were: non-English publications published prior to 2000, non-systematic review method (e.g., narrative review), main setting not specific to long-term care, study not focused on residents who have dementia, or study not focused on dementia as a condition (i.e., enteral treatment of undernutrition due to short term illness within persons with dementia).

A total of 10 systematic reviews were included in this umbrella review. Figure 1 gives an overview of the search strategy. The initial search yielded 478 publications and an additional 4 were found through hand searching. After duplicates were omitted, the titles and abstracts were assessed according to the inclusion and exclusion criteria. If it was not clear whether to include the paper based on the title and abstract, the full-text paper was retrieved and reviewed against the inclusion and exclusion criteria. A total of 25 full-text publications were reviewed and independently assessed for eligibility by two researchers (AC and SW). Discussion of these articles in relation to the inclusion and exclusion criteria was undertaken to achieve consensus and the final list of 10 publications was determined.

Figure 6.1: PRISMA Flow Diagram



The 10 publications were reviewed by two researchers (AC and SW). Quality of reviews was assessed according to Guyatt's guidelines to evaluate systematic reviews (Guyatt et al., 2015) and Khan's critical appraisal of systematic reviews (Khan et al., 2011). The articles were evaluated according to their focus, interventions and outcomes examined, main findings, strengths, and limitations.

6.4 Results

The reviews were assessed according to the research objectives, surveying the general types of interventions and outcomes considered, and examining the recommendations made pertaining to care aides and RDs. An overall summary of the reviews is included in Table 6.1 and the review recommendations made specifically regarding LTC staff, care aides, and RDs is included in Table 6.2.

Table 6.1: Examination of Review Studies Included in Umbrella Review						
Paper	Focus of Review	Study details: (i) Number(n) (ii) Date ranges (iii) Setting (iv) Location (v) Sample sizes	Methods	Main Findings	Limitations	Recommendations made re Care Aides or Dietitians (RD)
Abdelhamid et al., 2016	Evaluation of direct and indirect interventions to improve eating and drinking	(i) N=43 (ii) 1992-2012 (iii) LTC, group home, day centre, community (iv) Europe, North America, Brazil, Taiwan (v) 5-515	-Searched 13 databases (no language restrictions) -Intervention studies -Outcomes: nutrition/hydration status, intake, swallowing, cognitive/functional ability, QoL, cost-effectiveness, mortality -Interventions: Oral nutrition supplements of varying types (Supplements, food modification), swallowing problem management, eating assistance, social support) -Multiple reviewers assessed selection and validity -Validity assessed by Cochrane risk of bias tool -Meta-analysis and subgroup analysis -Included a lay-careperson directed investigation	-Findings were generally mixed or weak without sufficient evidence to suggest specific effective interventions -Some evidence to suggest use of oral nutritional supplements, food modification, and increased social/QoL aspects of eating assistance -Noted that strong social support around food and drink are key to QoL -Recommendation to increase the number of high quality studies to further investigate promising practices (oral nutrition supplements; pureed	-Most studies had small sample sizes (5 with >100) - Inclusion of studies not specific to residential LTC home population Studies often lacked details of diagnosis or stage -Broad range of interventions and outcomes assessed making it difficult to characterize the relationships and make specific recommendations	-General recommendations to increase staff assistance, increase meal-sharing with staff, increase staff training; no recommendations specific to care aides or RDs

				and reformed foods; thickened fluids; individual mealtime or between meal assistance; family style meals, meals shared with staff/carers; meals with facilitated social element; reminiscence cooking; finger foods)		
Chang et al., 2008	Review of literature to develop an understanding of feeding difficulty and delineate their antecedents and consequences	(i) N=71 (ii) 1981-2006 (iii) Not specified (iv) Not specified (v) Not specified	-Searched 4 databases (language filters not specified) -Used concept analysis -Considered persons with dementia or articles related to infants if they contributed conceptually to feeding difficulties in adults	Developed a 3-stage conceptual model describing feeding difficulty: antecedent causal factors (social interaction, perceptual deficits, poor motor control, cognitive impairment, psychosocial factors, dining environment, culturally appropriate food choices), manifestations of feeding difficulty (initiating feeding tasks, maintaining attention to feeding task, getting food	-Review process unclear -Lack of detail of review -Lacks a description of quality assessment of included studies -Use of reviewed studies in conceptual development unclear -Excluded 5 earlier studies because they had similar designs and results as more recent studies	-No recommendations specific to staff; no recommendations specific to care aides or RDs -a secondary paper from the review's data recommended consistent assignment of care aides to residents, use of non-nursing personnel to assist with feeding non-complex cases in order to free care aide time to assist with complex cases, and recommended RDs be included in

				<p>into the mouth, difficulty chewing food, difficulty swallowing food), and consequences or outcomes of feeding difficulty (inadequate food intake, weight loss, malnutrition, aspiration, pulmonary complications)</p> <p>-Feeding difficulties arise from both caregiver efforts and personal abilities and the concept model helps to provide a framework for giving direction on assessment</p>		monitoring malnutrition
Chaudhury et al., 2013	Examination of the role of the physical environment of nursing home dining rooms to support positive outcomes for residents with dementia	<p>(i) N=22</p> <p>(ii) 1996 – 2012</p> <p>(iii) LTC, adult day program</p> <p>(iv) Not specified</p> <p>(v) ≥ 6 (not stated except when small as a limitation, which occurred for 14 of the studies included)</p>	<p>-Searched 5 databases (all English)</p> <p>-12 were intervention studies; remainder were qualitative, mixed method, or other non-intervention</p> <p>-Many different outcomes considered including physiological and psychosocial aspects</p> <p>-Interventions: A number of intervention types were considered</p>	<p>Identified 7 therapeutic goals related to physical environment:</p> <p>-support functional ability</p> <p>-maximize orientation</p> <p>-provide sense of safety/security</p> <p>-create familiarity and homelikeness</p>	<p>-Inclusion of studies not specific to residential nursing home population (e.g., adult day program)</p> <p>-Several observational studies with non-specific</p>	<p>-general recommendations for staff participation in holistic person-centered care during dining in LTC, importance of staff education in interventions; no recommendations specific to care aides or RDs</p>

			<ul style="list-style-type: none"> -Multiple reviewers assessed selection and validity where quantitative and qualitative articles had differing criteria -Data synthesis was based on the validity assessment along with critical review of the main focus, research methods, findings, and limitations 	<ul style="list-style-type: none"> -provide optimal sensory stimulation -provide opportunities for social interaction -support privacy and personal control 	<ul style="list-style-type: none"> outcomes, small sample sizes -Limited explanation of process used in development of therapeutic goals -Noted difficulty in studies to assess nutritional outcomes given that timelines are often too limited -Noted difficulty in measuring outcome specific to interventions of environmental change because the change would affect staff and staff behaviours which may then confound outcome 	
Hines et al., 2010	Examination of the use of oral liquid nutrition supplements (OLNS) for residents with dementia	<ul style="list-style-type: none"> (i) N=15 (ii) 1998 – 2007 (iii) LTC (iv) Not specified (v) Unknown 	<ul style="list-style-type: none"> -Searched 14 databases (all English) and grey literature -All types of study designs were considered as were quantitative and qualitative studies -Interventions: Where OLNS were administered to improve protein and energy intake. 	<ul style="list-style-type: none"> Divided findings into prescription, administration, and effectiveness of OLNS -Prescription: most often made by physicians and sometimes by dietitians to treat poor intake and/or 	<ul style="list-style-type: none"> -Multiple factors make it difficult to decisively conclude whether OLNS are beneficial for residents with dementia (for example, if prescription practice or 	<ul style="list-style-type: none"> -Discussion of difficulty measuring effectiveness of interventions as staff and staffing could confound relationship of intervention and outcome

			<p>-Outcomes: There were many including those related to effectiveness (e.g. mortality, functional status, etc.) as well as to prescription and administration (e.g. staff views and management, etc.)</p> <p>-Considered persons with dementia</p> <p>-Rated quality of evidence by 2 reviewers using an appraisal checklist (JBI)</p>	<p>weight loss; little work to investigate root cause of impaired intake/weight loss done prior to prescribing</p> <p>-Administration: Not always provided to resident according to the prescription; staff assistance is an important factor; medication rounds may lessen wastage; significant amount is not consumed by residents with dementia</p> <p>-Effectiveness: No evidence for impacting morbidity or mortality; no evidence for an effect on functional status and weak evidence on slowing cognitive decline or improving energy intake; some evidence that may improve nutritional status and promote increase in body weight</p>	<p>administration was improved would effectiveness be impacted?)</p>	<p>-Recommendations include adequate staffing levels to allow for proper administration of OLNS in LTC; no recommendations specific to care aides; noted that oral nutrition supplements are ordered by dietitians</p>
--	--	--	---	---	--	--

Jackson et al., 2011	Assessment of interventions to encourage eating or minimize undernutrition for persons with dementia living in care facilities	(i) N=11 (ii) 2000 – 2008 (iii) LTC (iv) USA, Canada, Sweden, Finland, Spain, New Zealand (v) 9-62	-Searched for published and unpublished studies in a 3 step approach (English) -Designs: RCTs, CCTs, pre-post designs -Outcomes: A range were considered including dietary intake, nutritional status, anthropometry, functional -Interventions: A range including anything that was intended to promote dietary intake: education of staff, environment/foodservice modification. -Quality of evidence was assessed by two reviewers using JBI	-While evidence was not robust, there was some moderate evidence to show improvements in dietary intake or dietary status with staff education, simple environmental manipulations, introduction of background, feeding assistance, enhanced menus, decentralized food service, nutritional screening, increased dietetic time	-Limited time period considered -Broad spectrum of interventions and outcomes considered -Inability to compare effectiveness of different interventions due to heterogeneity	-Recommendations include educational training of staff; no recommendations specific to care aides; recommendations for RDs are to increase RD input into nutrition care and evaluation of intake
Leah, 2016	Identification of best practices to support eating in persons with dementia	(i) N=22 (ii) 2004 – 2015 Settings: long-term care, 1 rehab centre, 1 community-dwelling (iv) USA, Canada, Europe, Taiwan (v) Unknown (only some information provided)	-Searched 5 databases (English) -Intervention studies -Outcomes: Considered multiple outcomes related to nutritional health -Interventions: Considered several and grouped as educational, environmental, assistance with eating, and mixed -Multiple reviewers assessed selection and validity and used the	-Noted the importance of tailoring intervention to particular needs of individual Categorized findings into 4 types of interventions: -Education: training programs for staff positively impacted outcomes particularly when	-Inclusion of study with community dwelling or outpatient population -Wide range of interventions, variation in study methods and outcomes evaluated prevents assertion of	-Recommendations include increased education/training for staff, increased staff time, and clinical supervision of staff; no recommendations made specific to care aides or RDs

			<p>Quality Assessment Tool for Quantitative Studies followed by GRADE</p> <ul style="list-style-type: none"> -Studies included staff and person with dementia -Considered persons with dementia 	<p>education is paired with supervision</p> <ul style="list-style-type: none"> -Environmental or routine changes: mixed results found in part due to wide variation in interventions -Assistance with eating: positive outcomes observed when time spent by staff in assisting increased -Mixed interventions: 2 studies used multiple interventions, some benefit demonstrated by increased involvement of staff/volunteers during meals 	<p>specific recommendations</p> <ul style="list-style-type: none"> -Noted difficulty in translating results of studies when interventions performed by researchers rather than LTC staff -Noted confounding nature of increased attention regardless of specific intervention 	
Liu et al., 2014	Examine evidence in interventions to reduce mealtime difficulties for older adults with dementia	(i) N=22 (ii) 2004 – 2011 (iii) LTC (iv) USA, Canada, Europe, Taiwan (v) 12-226	<ul style="list-style-type: none"> -Searched 5 databases (English) -Intervention studies -Outcomes: Extremely broad range of outcomes considered from mealtime difficulties to weight and nutrition status -Interventions: Broad range of interventions considered grouped by supplementation, 	<p>Findings categorized according to 5 types of intervention:</p> <ul style="list-style-type: none"> -Nutritional supplementation: moderate evidence that high-calorie supplements can increase nutrient intake and weight but no changes observed in behavior 	<ul style="list-style-type: none"> -Wide range of interventions and outcomes examined -Inclusion of studies with non-nursing home populations or mixed geriatric inpatient and day program 	<ul style="list-style-type: none"> -Recommendation that appropriate training for care aides is necessary for improving nutritional outcomes; no recommendations specific to RDs

			<p>training/education, environment/routine modification, feeding assistance, mixed</p> <p>-Quality of evidence: Quality and strength of evidence rated by multiple reviewers using the quality assessment tool for quantitative studies followed by GRADE</p> <p>Graded the evidence for each of 6 nutritional outcomes: body weight, BMI, food intake, eating time, feeding difficulty, and agitation</p> <p>-Studies included staff and person with dementia</p> <p>-Considered persons with dementia and caregivers</p>	<p>or cognitive function, low evidence for use of appetite stimulants or modified food</p> <p>-Training/education: Mixed results; some decreases in feeding difficulty and increases in eating time shown with increased staff training, limited effect on intake or nutritional risk</p> <p>- Environment/routine modification: Mixed results and insufficient evidence to make recommendations</p> <p>-Feeding assistance: Moderate evidence to suggest increases in intake and in time to assist</p> <p>-Mixed intervention (environment/routine change combined with training or assistance): some evidence of increases to body weight and intake</p>	outpatient populations	
--	--	--	--	--	------------------------	--

Liu et al., 2015	Examine interventions aimed at optimizing eating performance for long-term care residents with dementia	(i) N=11 (ii) 1995 – 2011 (iii) LTC (iv) USA, Canada, Taiwan (v) Range unknown but included 530 adults with dementia and 86 nursing caregivers in total	-Searched 5 databases (English) -Intervention studies -Outcomes: Multiple but focused on eating performance and self-feeding -Interventions: Classified into four types (training programs, mealtime assistance, environment modification, multicomponent) -Quality of evidence assessed by two reviewers using the Quality Assessment Tool for Quantitative Studies followed by OCEBM level of evidence grading -Considered persons with dementia and caregivers	-Training programs for residents or nursing assistants suggested Montessori methods improved eating performance -Mealtime assistance from nursing caregivers helped improve eating performance -Environmental modification to address environmental factors was effective	-Wide date range of included studies -Limited overall description of the studies which were included -Specifically, limited description of measurement of outcome and intervention considered in studies (e.g., eating performance)	-Recommendations included education and training for care aides and one-on-one assistance at mealtimes; no recommendations specific to RDs
Watson and Green, 2006	Examination of interventions for feeding difficulty for older persons with dementia	(i) N=13 (ii) 1994 – 2002 (iii) LTC (iv) Sweden, UK, Belgium, USA (v) 2-24	-Searched 4 databases (English) -Multiple types of quantitative designs -Outcomes: Many types of outcomes were considered including weight/BMI, behaviours related to dementia, intake, time spent at meals -Interventions: Many types of interventions	-Some suggestion that use of music and use of prompting or reinforcing behaviours could be beneficial to enhancing feeding assistance, but results varied among studies -Major finding addressed the	-Most studies had very small sample sizes, non-experimental designs -Wide variety of interventions and outcomes examined so limited specificity of recommendations	-No recommendations specific to care aides or RDs

			<p>were considered, including staff assignment, nutritional assessment, behavioural, environmental/foodservice</p> <ul style="list-style-type: none"> -Quality of evidence assessed by two reviewers -Considered persons with dementia 	<p>difficulty of research in the area of feeding due to the presence of multiple confounding factors within long term care context</p> <ul style="list-style-type: none"> -Demonstrated a clear need for increased rigour in future studies involving nutrition and residents with dementia in long term care 	<ul style="list-style-type: none"> -inclusion of non-LTC populations in some studies -Out of the 13 papers included, only 2 published after 2000 	
Whear et al., 2014	Examination of direct or indirect mealtime interventions (not including nutritional supplementation or food fortification) for improving behavioural symptoms of residents with dementia in long term care	<ul style="list-style-type: none"> (i) N=11 (ii) 1994 – 2011 (iii) Residential care (iv) Canada, USA, Belgium, Sweden, Taiwan (v) 5-41 	<ul style="list-style-type: none"> -Searched 15 databases (no language restrictions) -Comparative study designs were considered -Outcomes: Behavioural and psychological symptoms -Interventions: Those aimed to improve routine, experience, or environment which were then categorized as music, food service, or environmental -Multiple reviewers assessed selection and validity - Included assessment of quality for all included studies 	<ul style="list-style-type: none"> -Noted limitations due to study quality in LTC research -Most of the studies showed positive effects with the strongest evidence coming from the investigation of music on various outcomes 	<ul style="list-style-type: none"> -Inconsistency in study interventions -Many studies did not have a formal dementia diagnosis noted -Potential publication bias due to studies missing from larger centers (e.g. UK) 	-No recommendations specific to care aides or RDs

			-Considered older adults living with dementia in residential care			
--	--	--	---	--	--	--

Overall the quality of evidence was low. Little overlap was observed in included studies between reviews, possibly owing to the variety of focuses of the ten systematic reviews. Nutrition care is a broad concept and these reviews addressed specific facets such as environment, foodservice/mealtime enhancement, feeding assistance, enhanced nutritional screening, use of nutrition supplements, and education/training for staff.

In terms of interventions considered, a wide variety were considered in these reviews. Generally, interventions included use of oral supplementation/food fortification (Abdelhamid et al., 2016; Hines et al., 2010; Jackson et al., 2011; Liu et al., 2014), eating assistance (Abdelhamid et al., 2016; Chang et al., 2008; Jackson et al., 2011; Leah et al., 2016; Liu, et al., 2014; Liu, et al., 2015), environmental modification (Chang et al., 2008; Chaudhury et al., 2013; Jackson et al., 2011; Liu et al., 2014; Liu et al., 2015; Whear et al., 2014); staff education or training (Jackson et al., 2011; Leah et al., 2016; Liu et al., 2014; Liu et al., 2015); and food service/food delivery modification (Jackson et al., 2011; Chaudhury et al., 2013; Watson & Green, 2006). Outcomes considered varied considerably including a range of psychological/psychosocial/behavioural measures, anthropometric measures such as weight and BMI, intake measures, functional measures such as eating ability/performance, satisfaction/perspective, and quality of life measures (Table 6.1).

Table 6.2: Examination of Recommendations Made Specifically to LTC Staff, Care Aides, and RDs			
Study	Recommendations for LTC staff generally	Recommendations specific to LTC care aides	Recommendations specific to Registered Dietitians (RDs)
Abdelhamid et al., 2016	-Recommended increasing social support around food and drink -Recommended increased staff assistance, increased staff training, and staff involvement at mealtimes	nil	nil

Chang et al., 2008	<p>-Noted that feeding is within the purview of nursing care, and the importance of skills and knowledge of staff in assisting with nutrition care</p> <p>-Noted that “the antecedents to feeding difficulty often are not appreciated [by staff] as conceptually different from feeding difficulty and may be confused during assessment and interventions”</p> <p>-Secondary paper detailing the results of the review recommended a multidisciplinary approach to address feeding difficulties and listed nurses, care aides, occupational therapists, physical therapists, speech therapists, family members, and volunteers</p>	<p>Secondary paper detailing results of the review described that care aides provide nearly all feeding assistance</p> <p>Secondary paper detailing results of review recommended consistent assignment of care aides and residents, use of volunteers to assist at mealtimes in order to free care aide time to attend to more complex resident cases; recommended further research specific to the effect of education and training on care aide knowledge/attitude/behavior when assisting in meal provision</p>	<p>Secondary paper detailing results of review did not include RDs in list of multidisciplinary care team; noted that RDs typically calculate calorie counts and assesses malnutrition; recommended involvement of RDs in monitoring malnutrition</p>
Chaudhury et al., 2013	<p>-Noted the importance of staff education in person-centered care related to physical environment (e.g., foodservice should limit excess noise, nursing staff should ensure clear dining rooms free of staff carts/tools)</p> <p>-Noted that person-centered care principles are key to supporting abilities and promoting connectedness</p>	nil	nil
Hines et al., 2010	<p>-Recommended treating oral nutrition supplements as a medication rather than a food in order to reduce staff using them in place of meals</p> <p>-Noted that inadequate staffing in LTC can lead to use of oral nutrition supplements as a meal replacement instead of as a supplement and can lead to problems with administration of prescribed oral nutrition supplements</p> <p>- Recommended sufficient staffing to enable mealtime assistance, to pour oral nutrition supplements from difficult</p>	nil	<p>No recommendations specific to RDs; noted that RDs as well as physicians prescribe oral nutrition supplements</p>

	packaging to more appropriate serving cups, and to ensure that supplements are given in small amounts at regular intervals		
Jackson et al., 2011	-Recommended increasing education and training of staff; regular repeating or updating of training of staff	nil	Recommendations to increase involvement of RDs in nutrition care in general, increase RDs in evaluation of intake
Leah, 2016	-Recommended staff training supplemented by supervision	nil	nil
Liu et al., 2014	-Recommended education and training for nursing, care aides and family caregivers	-Recommended appropriate training for care aides	nil
Liu et al., 2015	-Recommended one-on-one nursing assistance during mealtimes -Recommended staff training on mealtime assistance	-Recommended education and training for care aides, one-on-one care between care aide and resident during mealtime	nil
Watson and Green, 2006	-Noted importance of multidisciplinary team and listed geriatricians/psychogeriatricians, physiotherapists, speech language therapists and occupational therapists	nil	nil
Whear et al., 2014	-No recommendations made related to LTC staff	nil	nil

In addition to calls for further research, few specific recommendations were made (Table 6.1 and Table 6.2). The broad and general nature of the recommendations was likely due to the relatively low quality of evidence, heterogeneity of findings, and the wide range of interventions and outcomes considered. Although few studies differentiated between types of staff, recommendations regarding staff in LTC included need for increased training and education (Abdelhamid et al., 2016; Chaudhury et al., 2013; Jackson et al., 2011; Leah et al., 2016; Liu et al., 2014; Liu et al., 2015), and increased staff time/involvement (Abdelhamid et al., 2016; Hines et al., 2010). Two reviews made recommendations specific to care aides, calling for appropriate training/education (Liu et al., 2014; Liu et al., 2015) and 1 review recommended that care aides provide one-on-one assistance to residents with dementia (Liu et al., 2015). One review made recommendations specific to RDs in terms of generally increasing RD involvement in nutrition care and increasing RD involvement in evaluation of nutritional intake (Jackson et al., 2011).

6.5 Discussion

In 2013, Rolland and de Souto Barreto noted that therapeutic strategies in LTC are, for the most part, not evidence-based, owing in part to the dearth of research conducted in LTC at less than 2.5% of published research in older adult populations (Rolland & de Souto Barreto, 2013). Similarly, this umbrella review found that while there is heightened interest in the topic of effective nutritional care for LTC residents with dementia, research conducted within LTC is of generally low quality with inconsistency in outcomes investigated or considered important (Aselage et al., 2011).

Improvements to anthropometric, functional, and quality of life outcomes were observed in the wide variety of interventions examined and no negative outcomes were reported. Of particular importance are the improvements made to quality of life given that dementia is an incurable

disease of decline. Though not specific to residents with dementia, in a study examining the relationship between 11 domains of quality of life among LTC residents, food enjoyment was found to be a significant positive predictor of satisfaction with LTC (Burack et al., 2012).

It is not surprising that the main recommendations made in these reviews involved LTC staff as it is generally accepted that in order to change a care outcome, staff care practices must be targeted. In a review of LTC staff practices, Low et al. (2015) found that there is a strong evidence base regarding the relationship between staff care practices and resident outcomes, that staff behaviours are easier to target than outcomes, and that interventions which were not successful in improving staff practices also did not improve resident outcomes (Low et al., 2015). However, organizational factors must be in place to support staff practices in order for them to be successfully implemented and maintained (Elliot et al., 2012). An examination of dementia care workers concluded that while education is an essential component of providing quality care, particularly person-centered care, education can contribute to staff distress when they are unable to perform according to the training due to organizational constraints (Cook et al., 2012).

Notable was a lack of discussion addressing severity of dementia and the impact on nutritional care strategies. In addition to calling for increased rigour in future studies, Watson and Green (2006) criticized the state of science for failing to consider dementia severity when evaluating interventions. That is, severity or stage of dementia is an important factor that may confound the impact of any intervention with some being more successful at earlier or later stages of the disease trajectory (Watson & Green, 2006). The type of dementia may also be an important consideration that was not addressed by any of the reviews; heterogeneity of results may be, in part, owing to the heterogeneity of diseases resulting in dementia.

The majority of reviews overlapped in recommending increased education or training for LTC staff as an effective strategy to enhance nutrition care for residents with dementia. A quasi-experimental feeding skills training intervention trial was found to increase care aide knowledge and translate into enhanced care for LTC residents with dementia through significantly lengthened resident time at meals, more supportive eating, and increased intake (Chang & Lin, 2005). Amella (2004) posits that attention must be paid to not only what residents eat but how they eat and are supported to eat, but cautions that education or training must be paired with adequate staff time and an appreciation that residents with dementia often present challenges to mealtimes and nutrition care (Amella, 2004). Keller (2016) agrees that more robust research on interventions that address the many components that comprise nutrition care are needed (Keller, 2016).

Related to the need to address complexity when considering staff training is the need for training to be long-term and supported by involvement or supervision that reinforces the teachings (Kuske et al., 2007; Rahman et al., 2012). A training intervention aimed at increasing LTC care aide knowledge and behaviours around nutrition care for LTC residents randomized among LTC homes found that pairing education with supportive supervision and reinforcement of concepts was effective to maintain resident nutritional status in comparison to residents in LTC that did not receive the education and supervision component (Gaskill, 2009).

The most pertinent finding from this umbrella review is the lack of specificity regarding type of staff when making recommendations related to nutrition care for residents with dementia. Perhaps studies regard staff as a unified concept under the auspices of person-centered care, in recognition of the need for all staff working within the LTC setting to perform in concert.

However, the specificities of staff job duties, knowledge, and abilities are of appropriate concern when formulating recommendations.

Particularly concerning was the near absence of mention of RDs in the review articles. Given that RDs possess specialized training in nutrition care, the lack of mention in the majority of the reviews is of concern. A seminal study by Keller et al. (2003) found that enhanced RD time in LTC was effective in preventing or halting weight loss among residents with dementia (Keller et al., 2003). In a qualitative examination of LTC staff's perception of factors that could influence malnutrition treatment, education from RDs and interdisciplinary cooperation were listed as key, in addition to further education for nursing staff (Roller et al., 2016). The collaboration between RDs and other LTC staff via 'meal rounds' has been described as an effective way to enact nutrition care for LTC residents (Keller et al., 2006) and a recent literature review listed engaging the service of RDs as an overall recommendation to optimize nutrition care for persons with dementia (Cole, 2012). In a recent narrative review, Douglas and Lawrence asserted that RDs are critical members of interdisciplinary team care in LTC and can bring about effective change that can improve nutrition care and quality of life for LTC residents (Douglas & Lawrence, 2015).

The lack of specificity distinguishing the role of care aides from other direct care providers such as registered nurses or licensed practical nurses is a gap in that each of these groups possesses very different levels of training and responsibility regarding care of LTC residents, including nutrition care. Not only is more research required related to specificity of care aide education and training, but also on the interaction between care aide and resident with dementia, and the influence this has on nutritional outcomes (Aselage et al., 2011). Together, the lack of attention

to RDs and care aides represents a true gap that must be addressed in order for recommendations to enhance nutrition care for residents with dementia to be effective.

Future research investigation of nutrition care for LTC residents with dementia should not only be more rigorous and should include translational strategies to implement research findings into practice, but should focus on the specific abilities and skills of each type of staff within the LTC and person-centered care context.

6.6 Limitations

A limitation of this umbrella review is the inclusion of only English-language articles from high income countries. Another limitation is the lack of generalizable recommendations, due in part to the broad scope, but also due to the overall low quality of studies and the inherent lack of consensus on nutrition-related outcomes within the disease states that comprise dementia. The broad scope of the inquiry is a strength of this study, in consolidating and summarizing the state of the evidence regarding nutrition care for persons with dementia in LTC. This inquiry exposed a gap in the knowledge related to care staff and nutrition care provision in LTC in general.

Chapter 7.0 Discussion

The studies presented in the preceding three chapters addressed nutrition care for residents with dementia within the LTC setting from several vantages, specifically from the perspectives of care aides and registered dietitians, and also from the broader approach of examining the state of the formal evidence-base. The first study identified the roles and responsibilities of nutrition care for residents with dementia from the perspective of care aides working in rural and urban long-term care homes. The second study examined the role of registered dietitians in nutrition care for residents with dementia in urban and rural long-term care settings. The third study provided an overview of the current literature related to nutrition care for residents with dementia in long-term care homes.

The aim of this work was to make a novel contribution to the literature related to nutrition and dementia care. Together, these studies address an important gap in knowledge in evidence based practice in nutrition care for residents with dementia living in LTC homes. Given the importance of nutrition to physical health and quality of life, this is an area of great significance. Taken together, the studies elucidate key aspects related to person-centered care and quality of life for these residents, illuminating areas for future intervention and enhancement of care.

In this discussion the objectives and major findings from each study are outlined, and the broader implications of these studies in the field of dementia care is considered. Finally, the general limitations of the work are presented along with considerations for future research.

7.1 Nutrition Care for Residents with Dementia in Rural and Urban Long-term Care Homes: Perspectives of Care Aides (Study 1)

The objective of this study was to examine nutrition care for residents with dementia in LTC from the perspective of care aides. Care aides are responsible for the majority of direct care within the LTC context, and are the key staff who assist residents in accomplishing activities of daily living such as eating and drinking. As seen in this study, the day to day decisions regarding nutrition care are most often made at the direct interface between care aide and resident. Each nutrition care decision, from timing, context, and environment in which meals are provided, to choice and delivery of foods, could represent an execution of policy and evidence. Many of these decisions may occur at the macro planning level and can be said to frame nutrition care (e.g., menu planning, dining room environment). However, most decisions occur in the immediate moment of food provision (what is offered or not offered, how it is offered, when/where it is offered) and are enacted by a resident-care aide dyad. Both resident-level and system-level information is taken into account and integrated by the care aides and resident in the decision-making process.

Nutrition care is not comprised of discrete activities; it is executed within a dynamic context in which care providers must consider individual resident characteristics and needs, system/institutional factors, philosophies of care, and ever-changing contextual factors. While care aides voiced an appreciation of the importance of nutrition care to the health and well-being of residents with dementia, discussion of how to potentially achieve this were limited, focused almost exclusively on the mechanistic aspects of getting food into the resident, with little description of the important social aspects, interaction, and pleasure related to eating.

Person-centered care (PCC) represents a complex philosophical orientation to dementia care where care needs are continually renegotiated within a changing context with unpredictable resident needs. Negotiation of what constitutes a PCC action in terms of nutrition care is difficult for care aides and may require thorough mentorship, particularly in light of the broader aspects related to nutrient requirements and adequate intake. For example, how does a care aide respect the individual's right to refuse food or drink, yet ensure that adequate hydration is achieved? Many advocate for structural empowerment of care aides as a method to enhance quality of care overall in LTC (Chaudhuri, et al., 2013); however, without thorough mentoring in nutrition care, empowerment is not without risk.

As well, when considering Sackett's model of evidence-based practice (Sackett, 1996), care aides often function concurrently in the position of clinical expertise and the position of patient/resident preference when caring for residents with dementia who are less able to communicate desires and preference for care. Acting simultaneously as care provider and on behalf of the care receivers a challenge to providing effective care in and of itself, but is further complicated considering the dearth of evidence to support nutrition care practices in LTC. The scarcity of evidence-based care recommendations or care guidelines related to nutrition care and dementia further entrenches anecdotal coping skills learned on the job, which may or may not be effective.

The findings of this study suggest that enhanced practical training, greater coordination of nutrition care, supportive supervision, and adaptive mentorship could support care aides in enhancing nutrition care for residents with dementia.

7.2 The Downstream Role of Registered Dietitians Providing Nutrition Care for Residents with Dementia in the Long-term Care Setting (Study 2)

An evidence-based practice lens was used to examine the role of RDs in the LTC context related to nutrition care of residents with dementia. Given that dementia represents illnesses that are chronic and progressive in nature, the more proactive or upstream an intervention is, the more effective that measures of secondary prevention of symptom exacerbation or efforts to delay progression can be. Such is the case with prevention of malnutrition in dementia, and certainly such is the case with regard to PCC efforts to maximize enjoyment and pleasure from dining. However, as seen in this study, the role of the RD in nutrition care for residents with dementia in LTC is decidedly downstream due to a number of interrelated systemic operational factors.

RDs possess specialized expertise in nutrition care and are crucial members of the interdisciplinary LTC team (Lilly & Gaudet-LeBlanc, 1998; Jurkowski, 1998; Roberts, 2011). However, with respect to dementia, the RDs in this study reported not being involved in care via request for consultation until the resident was far along the disease trajectory and experiencing consequences of malnutrition. Factors such as limited resources, high ratios of resident to RD caseload, operational and departmental isolation or siloing, reliance on relationships rather than process, and limited or stereotyped understandings of what a RD role encompasses by others limit the involvement of RDs and push RD care downstream in the dementia trajectory. Intervening downstream could exacerbate misunderstandings of RD abilities, given that ability to reverse consequences of malnutrition may be less successful than earlier preventative care.

7.3 Nutrition Care for Residents with Dementia in Long-term Care: An Umbrella Review of Current Evidence

The aim of this umbrella review was to comprehensively examine the peer-reviewed literature and ascertain from systematic reviews the current evidence-based practices recommended to support or enhance nutritional care of residents with dementia in the LTC context. Particular attention was paid to the recommendations related to care aides or to RDs, and an overview of interventions and outcomes in terms of consistency was sought.

While it is clear that nutrition care is an important area of interest, as evidenced by inclusion of 10 systematic reviews addressing the topic, little consistency in terms of interventions or outcomes was observed. The quality of evidence was rated as low to moderate, and while there were many recommendations made regarding staff in general, there was very little in terms of recommendations made specific to care aides or RDs. In fact, only 3 recommendations were made regarding care aides specifically, and only one review made recommendations specific to RDs. Given that care aides are responsible for the majority of direct care practices related to executing nutrition care for residents with dementia and RDs are the allied health providers who possess a specific knowledge base and skillset focused on effective, evidence-based practice of nutrition care, the general lack of attention to these two categories of care staff in the evidence base is disappointing.

7.4 Relationship between Studies and Overall Conclusions

It is well-established that nutrition plays a vital role in dementia care. Dementia is associated with increased risk of impairment in eating ability and malnutrition (Mitchell et al., 2009; Smith, 2011). Malnutrition can accelerate cognitive decline, increase secondary negative outcomes (e.g.,

unwanted weight gain or loss, muscle wasting, infection, poor wound healing, pressure ulcer formation), and increase morbidity (Chen et al.; Mitchell, 2009; Smith & Greenwood, 2008), while optimizing nutritional status can reduce disease co-morbidity and prevent accelerated decline in physical health (Keller et al., 2003). In recent years, there has been increasing appreciation for the role of nutrition care in enhancing quality of life of LTC residents with dementia (Bostrom, 2011; Murphy et al., 2017).

In spite of this appreciation, little has been done to examine the role of the RD in enhancing nutrition care for LTC residents with dementia, and only one known study, by Keller et al. (2003) examined the effectiveness of RD care on physical health of LTC residents with dementia. In a comprehensive examination of factors that contribute to nutritional intake in LTC, Keller et al. (2017) found evidence to suggest that adequate RD time within LTC trended to increased protein intake among LTC residents. Though the study was not focused solely on residents with dementia, the authors also found that PCC practices were associated with better nutritional intake and concluded that adequate RD time in LTC is needed (Keller et al., 2017).

Among even those with severe dementia, eating and drinking remain a source of pleasure (Pivi et al., 2012). In addition to aiding the nutritional health of residents with dementia, nutrition care interventions have been shown to increase overall quality of life measures (Bostrom, 2011; Keller, 2016; Smith, 2011). PCC is known to be a defining feature of good nutritional care for residents with dementia within the LTC setting (Murphy et al., 2017; Reimer & Keller, 2009). Despite this, many of the studies on nutrition in LTC lack PCC measurements or PCC-related outcomes (Dominguez & Barbagallo, 2017). As seen in the umbrella review, there was inconsistency in interventions and outcomes, and few measurements of PCC practices or outcomes. Lann-Wolcott et al. (2011) examined the utility of PCC measurement scales in care

aide-resident with dementia interaction in LTC and concluded that individual resident conceptions of what constitutes ideal PCC will impede a one-size fits all approach to care provision, but teaching PCC skills as well as how to adapt them would be of benefit to care aides.

A research study conducted in the UK by Murphy et al. (2017) found that PCC is an overarching concept central to evidence-based nutrition care for residents with dementia in LTC homes (Murphy et al., 2017). Caspar et al. (2018) found that PCC practices by care aides, measured by empowerment and autonomy, could be enhanced through supportive supervision by nurses or licensed practical nurses. While their survey was general in terms of care practices and not specific to nutrition care, it is possible that a similar relationship could exist whereby care aides are better able to implement PCC nutrition care if supported by RDs who guide the evidence-based practice.

A Canadian research team recently conducted a narrative review and developed a conceptual framework of PCC in an effort to facilitate operationalizing PCC in healthcare (Santana et al., 2017). The framework is made up of three core components: structure, process, and outcomes. The outcomes are related to benefits that could be experienced by patients or residents, the processes are actions that can be undertaken by healthcare providers (communication, integration of care, respect), and structures are supports that must exist operationally in order for processes and outcomes to be achieved. These include an organizational culture that is committed to PCC, supporting the workforce in PCC, and creating supportive environments that accommodate PCC practices. The findings of this study certainly support the tenets of this conceptual framework; many of the impediments to PCC related to nutrition care experienced among the care aide and

RDs who participated correspond to the organizational structures, environments, and ineffective communication or integration of care.

While RDs are well positioned to translate evidence on nutrition care practices to enhance physical health and quality of life for residents with dementia and support and mentor LTC staff in execution of PCC nutrition care practices, it is the care aides who perform most of the tasks and make in the moment decisions with residents that comprise nutrition care. The responsibility assigned to care aides is increasing with the increasing acuity of care in LTC homes. Without support and mentorship by qualified experts in nutrition care, care aides will continue to rely on informal communication and anecdotal coping mechanisms while focusing on the mechanistic feeding aspects of nutrition care.

Berta et al. (2013) posit that the role of the care aide in Canadian health care is changing, with increased expectations, accountabilities, and responsibility. These authors conclude that we must re-conceptualize care aides from task workers to knowledge workers, as they are now asked to think critically, accomplish delegated care tasks, and execute evidence-based care decisions in an increasingly complex milieu, and as such, we must better equip them to fulfill these responsibilities (Berta, et al., 2013). A logical next step in the context of nutrition care for LTC residents with dementia is enhanced communication and collaboration between care aides and RDs.

As demonstrated in this research, the challenges experienced in executing PCC nutrition care for LTC residents with dementia are exacerbated by rurality. That is, the rural context functions as another layer that must be navigated by care staff when performing nutrition care, from the reduced availability of specialist and allied providers such as RDs, to the more limited food choice for residents due to smaller menus and fewer food delivery sources in rural areas.

Interventions meant to enhance nutrition care for LTC residents with dementia must consider factors specifically related to rural context in order to be successful within rural LTC homes.

7.5 General Limitations

There are several limitations associated with these findings. First, the qualitative nature of the inquiries, while essential, may be limited with respect to generalizability. As well, the deeper understanding gained from these qualitative projects does not provide direction as to the most effective area to intervene. This research took place in a specific geographic location which may impede transferability of findings to other locations. The inclusion of four LTC homes within the same region may be a limitation in that no comparison of jurisdictional policies that impact care aide perspectives of nutrition care could be undertaken.

As well, the broad nature of inquiry may be seen as a limitation. Viewing nutrition care holistically rather than a focused examination of a particular aspect such as hydration is challenging, and the broad overview is then limited in terms of developing discrete, specific recommendations. In terms of the systematic reviews examined, limiting the search to English could have been a limitation, as perhaps publications in non-English journals were missed. The focus on the formal evidence base could be a limitation of these studies; though common practice guidelines were examined, perhaps a thorough examination of the grey literature could reveal relevant information that could be useful to consider.

The focus on care aides and RDs is incomplete without attention to the registered nurses and licensed practical nurses who may play an important intermediary role, as well as other allied health providers, directors of care, and dietary staff. Not including these categories of care staff, though practical, is a limitation.

7.6 Implications for Practice and Future Research

Several practical recommendations can be made based on the findings of these studies. First, the skillset and knowledge of RDs can be better leveraged to support care aides in executing nutrition care for residents with dementia. Communication and collaboration between these two categories of care providers in LTC can and should be enhanced. Future research should examine RD function in a supportive supervision role with care aides, and the impact that this could have on resident health outcomes and quality of life.

Consensus on key resident outcomes is needed in order to better test interventions and strategies to enhance nutrition care for residents with dementia, and should be a focus of future research. Similarly, specificity of type and severity of dementia is needed in future research efforts in addition to specificity of recommendations for specific categories of staff. That is, it would be prudent for future research to specify which category of staff is responsible for implementing and executing recommended practices. As well, the complexity of the LTC context and the progressive nature of dementing illnesses must be considered when attending to nutrition care. Involvement of RDs further upstream in the dementia trajectory should be examined to determine potential health improvements.

Nutrition care is of critical importance when considering care for persons with dementia in LTC. Interventions that are able to demonstrate enhanced nutrition care for these residents have potential to dramatically improve secondary complications of malnutrition such as pressure ulceration and dysphagia, and have strong potential to positively impact resident quality of life. Increasing the evidence base and ensuring that PCC observations and outcomes are assessed are important next steps in research on nutrition and dementia.

Taken together, these studies demonstrate the need to enhance the evidence base, while better utilizing the skillsets of RDs and building communication and professional relationships between care aides and RDs in the LTC context.

Chapter 8.0: References

- Abdelhamid, A, Bunn, D, Copley, M, Cowap, V, Dickinson, A, Gray, L, Howe, L, Killett, A, Lee, J, Li, F, Poland, F, Potter, J, Richardson, K, Smithard, D, Fox, D, Hopper, L. (2016) Effectiveness of interventions to directly support food and drink intake in people with dementia: systematic review and meta-analysis. *BMC Geriatrics*. 16(26): 1 – 18.
- Ahmed, R. M., Irish, M., Kam, J., van Keizerswaard, J., Bartley, L., Samaras, K., Hodges, J. R., & Piguet, O. (2014). Quantifying the eating abnormalities in frontotemporal dementia. *JAMA Neurol*, 71(12), 1540-1546. doi: 10.1001/jamaneurol.2014.1931
- Albanese, E., Davis, B., Jonsson, P. V., Chang, M., Aspelund, T., Garcia, M., Harris, T., Gudnason, V., & Launer, L. J. (2015). Overweight and Obesity in Midlife and Brain Structure and Dementia 26 Years Later: The AGES-Reykjavik Study. *American Journal of Epidemiology*, 181(9), 672-679. doi: 10.1093/aje/kwu331
- Allen, V, Methven, L, Gosney, M. (2013) Use of nutritional complete supplements in older adults with dementia: Systematic review and meta-analysis of clinical outcomes. *Clinical Nutrition*. 1- 8.
- Aliani, M., Udenigwe, C. C., Girgih, A. T., Pownall, T. L., Bugera, J. L., & Eskin, M. N. (2013). Aroma and taste perceptions with Alzheimer disease and stroke. *Crit Rev Food Sci Nutr*, 53(7), 760-769. doi: 10.1080/10408398.2011.559557
- Alzheimer's Association. (2014). 2014 Alzheimer's disease facts and figures. *Alzheimers Dement*, 10(2), e47-92.
- Alzheimer Disease International (ADI) (2013). World Alzheimer Report 2013, Journey of Caring: An Analysis of Long-term Care for Dementia. Global Observatory for Ageing and Dementia Care; London, UK: Alzheimer Disease International. <http://tinyurl.com/ksqrwd6> (accessed 20 February 2018)
- Alzheimer Society Canada. (2010). Rising Tide: The Impact of Dementia on Canadian Society. <http://www.alzheimer.ca/en/Get-involved/Raise-your-voice/Latest-info-stats/Rising-Tide>
- Alzheimer Society Canada. (2011). Guidelines for Care: Person-centered care of people with dementia living in care homes. Canada.
- Alzheimer Society Canada. (2015a, June 24, 2014). Living with dementia - Caring for Someone with Dementia: Middle Stage what to expect. Retrieved August 11, 2015, from <http://www.alzheimer.ca/en/Living-with-dementia/Caring-for-someone/Middle-stage>
- Alzheimer Society Canada. (2015b, April 11, 2014). Living with Dementia: Planning for the Late Stage. Retrieved August 11, 2015, from <http://www.alzheimer.ca/en/Living-with-dementia/Caring-for-someone/Late-stage-and-end-of-life/Planning-for-the-late-stage>
- Alzheimer Society Canada. (2015c). Planning for the Future. Retrieved August 4, 2015, 2015, from <http://www.alzheimer.ca/en/Living-with-dementia/Planning-for-the-future>
- Amella, E. J. (2004). Feeding and hydration issues for older adults with dementia. *Nurs Clin North Am*, 39(3), 607-623. doi: 10.1016/j.cnur.2004.02.014

- Anderson, L. A., Day, K. L., Beard, R. L., Reed, P. S., & Wu, B. (2009). The public's perceptions about cognitive health and Alzheimer's disease among the U.S. population: a national review. *Gerontologist*, 49 Suppl 1, S3-11. doi: 10.1093/geront/gnp088
- Aparanji, K. P., & Dharmarajan, T. S. (2010). Pause before a PEG: A feeding tube may not be necessary in every candidate! *J Am Med Dir Assoc*, 11(6), 453-456. doi: 10.1016/j.jamda.2009.11.016
- Armstrong, P., and Armstrong, H. (2008). *About Canada: Health Care*. Canada: Fernwood Publishing.
- Armstrong, P., Boscoe, M., Clow, B., Grant, K., Haworth-Brockman, M., Jackson, B., Pederson, A., Seeley, M. and Springer, J. (2009). *A Place to Call Home: Long-term Care in Canada*. Canada: Fernwood Publishing.
- Armstrong, R. (2015). Dementia with Lewy Bodies In C. Martin, Preedy, V (Ed.), *Diet and Nutrition in Dementia and Cognitive Decline*. London: Elsevier.
- Aselage, M, Amella, E, Watson, R. (2011) State of the science: Alleviating mealtime difficulties in nursing home residents with dementia. *Nursing Outlook*. 59: 210 – 214.
- Bach-Faig, A., Berry, E. M., Lairon, D., Reguant, J., Trichopoulou, A., Dernini, S., Medina, F. X., Battino, M., Belahsen, R., Miranda, G., & Serra-Majem, L. (2011). Mediterranean diet pyramid today. Science and cultural updates. *Public Health Nutr*, 14(12a), 2274-2284. doi: 10.1017/s1368980011002515
- Banerjee, A. (2007). *An Overview of Long-term Care in Canada and Selected Provinces and Territories*. Toronto.
- Barbour, R. (2005) Making sense of focus groups. *Medical Education*. 39(7): 742 – 750.
- Barnes, D., & Yaffe, K. (2011). The projected effect of risk factor reduction on Alzheimer's disease prevalence. *The Lancet Neurology*, 10(9), 819-828. doi: [http://dx.doi.org/10.1016/S1474-4422\(11\)70072-2](http://dx.doi.org/10.1016/S1474-4422(11)70072-2)
- Barnes, D. E., & Yaffe, K. (2011). The projected effect of risk factor reduction on Alzheimer's disease prevalence. *Lancet Neurol*, 10(9), 819-828. doi: 10.1016/s1474-4422(11)70072-2
- Batchelor-Aselage, M., Amella, E., Rose, S., & Bales, C. (2015). Dementia-Related Mealtime Difficulties: Assessment and Management in the Long-term Care Setting. In C. Bales, J. Locher & E. Saltzman (Eds.), *Handbook of Clinical Nutrition and Aging* 3rd ed (pp. 287-301). New York: Humana Press.
- Beattie, E., O'Reilly, M., Strange, E., Franklin, S., & Isenring, E. (2014). How much do residential aged care staff members know about the nutritional needs of residents? *International Journal of Older People Nursing*, 9(1), 54-64. doi: 10.1111/opn.12016
- Bell, C. L., Lee, A. S., & Tamura, B. K. (2015). Malnutrition in the nursing home. *Curr Opin Clin Nutr Metab Care*, 18(1), 17-23. doi: 10.1097/mco.0000000000000130
- Bell, C. L., Tamura, B. K., Masaki, K. H., & Amella, E. J. (2013). Prevalence and Measures of Nutritional Compromise Among Nursing Home Patients: Weight Loss, Low Body Mass Index, Malnutrition, and Feeding Dependency, A Systematic Review of the Literature. *Journal of the*

- American Medical Directors Association, 14(2), 94-100. doi: <http://dx.doi.org/10.1016/j.jamda.2012.10.012>
- Bennett, M, Ward, E, Scarinci, N. (2014) Perspectives on mealtime management in residential aged care: Insights from a cross-disciplinary investigation. *Journal of Nutrition in Gerontology and Geriatrics*. 33: 325 – 339.
- Berta, W., Laporte, A., Deber, R., Baumann, A., & Gamble, B. (2013). The evolving role of health care aides in the long-term care and home and community care sectors in Canada. *Human Resources for Health*, 11, 25-25. doi: 10.1186/1478-4491-11-25
- Black, J. L., Dunham, R., & Kafka, T. (2013). A study of challenges and opportunities for long-term care dietitians in British Columbia. *Can J Diet Pract Res*, 74(3), 131-137. doi: 10.3148/74.3.2013.131
- Bowman, J. J., & Keller, H. H. (2005). Assessing nutritional risk of long-term care residents. *Can J Diet Pract Res*, 66(3), 155-161. doi: 10.3148/66.3.2005.155
- British Columbia Community Care and Assisted Living Act Residential Care Regulations (2009), retrieved from: << <http://www.health.gov.bc.ca/pho/community-care-assisted-living-act.html>>> January 23, 2015.
- Brook, S. (2014). Nutrition and dementia: what can we do to help? *British Journal of Community Nursing*, S24-27.
- Brooke, J., & Ojo, O. (2015). Enteral nutrition in dementia: a systematic review. *Nutrients*, 7(4), 2456-2468. doi: 10.3390/nu7042456
- Brooker, D. (2003). What is person-centred care in dementia? *Reviews in Clinical Gerontology*, 13(03), 215-222. doi: doi:10.1017/S095925980400108X
- Brooker, D. (2007). *Person-centered Dementia Care: Making Services Better*. London: Jessica Kingsley Publishers.
- Burack, O, Weiner, A, Reinhardt, J, Annunziato, R. (2012) What matters most to nursing home elders: quality of life in the nursing home. *Journal of the American Medical Directors Association*. 13: 48 – 53.
- Buykx, P., Humphreys, J., Wakerman, J., & Pashen, D. (2010). Systematic review of effective retention incentives for health workers in rural and remote areas: Towards evidence-based policy. *Australian Journal of Rural Health*, 18(3), 102-109. doi: 10.1111/j.1440-1584.2010.01139.x
- Cammer, A., Morgan, D., Stewart, N., McGilton, K., Rycroft-Malone, J., Dopson, S., & Estabrooks, C. (2014). The Hidden Complexity of Long-Term Care: How Context Mediates Knowledge Translation and Use of Best Practices. *Gerontologist*, 54(6), 1013-1023. doi: 10.1093/geront/gnt068
- Caputo, M., Monastero, R., Mariani, E., Santucci, A., Mangialasche, F., Camarda, R., Senin, U., & Mecocci, P. (2008a). Neuropsychiatric symptoms in 921 elderly subjects with dementia: a comparison between vascular and neurodegenerative types. *Acta Psychiatrica Scandinavica*, 117(6), 455-464. doi: 10.1111/j.1600-0447.2008.01175.x

- Caputo, M., Monastero, R., Mariani, E., Santucci, A., Mangialasche, F., Camarda, R., Senin, U., & Mecocci, P. (2008b). Neuropsychiatric symptoms in 921 elderly subjects with dementia: a comparison between vascular and neurodegenerative types. *Acta Psychiatr Scand*, 117(6), 455-464. doi: 10.1111/j.1600-0447.2008.01175.x
- Caspar, S, Le, A, McGilton, K. (2018) The influence of supportive supervisory practices and health care aides' self-determinism on the provision of person-centered care in long-term care facilities. *Journal of Applied Gerontology*. 1 – 19.
- Cereda, E, Klersy, C, Bonardi, C, Quarleri, L, Cappellos, S, Turri, A, Rondanelli, M, Caccialanza, R (2016) Nutritional status in older persons according to healthcare setting: A systematic review and meta-analysis of prevalence data using MNA. *Clinical Nutrition* 35: 1282 – 1290.
- Chang, C., & Lin, L. (2005). Effects of a feeding skills training programme on nursing assistants and dementia patients. *Journal of Clinical Nursing*, 14(10), 1185-1192. doi: 10.1111/j.1365-2702.2005.01240.x
- Chang, C, Roberts, B. (2008) Feeding difficulty in older adults with dementia. *Journal of Clinical Nursing*. 17: 2266 – 2274.
- Chang, C, Roberts, B. (2011) Strategies for feeding patients with dementia. *American Journal of Nursing*. 111(4): 36 – 44.
- Chang, H. C., Russell, C., & Jones, M. K. (2010). Implementing Evidence-Based Practice in Taiwanese Nursing Homes: Attitudes and Perceived Barriers and Facilitators. *Journal of Gerontological Nursing*, 36(1), 41-48.
- Chapman, S. P., S. (2008). *Rurality and Ageing Well: 'A Long Time here'*. In N. Keating (Ed.), *Rural Ageing: A Good Place to Grow Old?* Bristol: The Policy Press.
- Chare, L., Hodges, J. R., Leyton, C. E., McGinley, C., Tan, R. H., Kril, J. J., & Halliday, G. M. (2014). New criteria for frontotemporal dementia syndromes: clinical and pathological diagnostic implications. *J Neurol Neurosurg Psychiatry*, 85(8), 865-870. doi: 10.1136/jnnp-2013-306948
- Charmaz, K. (2006). *Constructing Grounded theory: A Practical Guide through Qualitative Analysis*. London: Sage.
- Charmaz, K. (2014). *Constructing Grounded Theory*, 2nd ed. Los Angeles: Sage.
- Chaudhuri, T, Yeatts, D, Cready, C. (2013) Nursing aide decision-making in nursing homes: Factors affecting empowerment. *Journal of Clinical Nursing*. 22: 2572 – 2585.
- Chaudhury, H, Hung, L, Badger, M. (2013) The role of physical environment in supporting person-centered dining in long-term care: A review of the literature. *American Journal of Alzheimer's Disease and Other Dementias*. 28(5): 491 – 500.
- Chen, C, Schilling, L, Lyder, C. (2001) A concept analysis of malnutrition in the elderly. *Journal of Advanced Nursing*. 36,(1): 131-142.

- Chi, L.-W., Lin, S.-C., Chang, S.-H., & Wu, H.-S. (2014). Factors Associated With Hyperphagic Behavior in Patients With Dementia Living at Home. *Biological Research For Nursing*. doi: 10.1177/1099800414562025
- Chiu, M., Chen, T., Yip, P., Hua, M., & Tang, L. (2006). Behavioral and Psychologic Symptoms in Different Types of Dementia. *Journal of the Formosan Medical Association*, 105(7), 556-562. doi: [http://dx.doi.org/10.1016/S0929-6646\(09\)60150-9](http://dx.doi.org/10.1016/S0929-6646(09)60150-9)
- Chiu, M. J., Chen, T. F., Yip, P. K., Hua, M. S., & Tang, L. Y. (2006). Behavioral and psychologic symptoms in different types of dementia. *J Formos Med Assoc*, 105(7), 556-562. doi: 10.1016/s0929-6646(09)60150-9
- CIHI. (2010). Caring for Seniors with Alzheimer's Disease and Other Forms of Dementia. <https://secure.cihi.ca/estore/productFamily.htm?locale=en&pf=PFC1534>
- CIHI. (2011). Health Care in Canada 2011: A Focus on Seniors and Aging. <https://secure.cihi.ca/estore/productSeries.htm?pc=PCC64>
- CIHI. (2013). When a Nursing Home is Home: How Do Canadian Nursing Homes Measure Up on Quality? <https://secure.cihi.ca/estore/productFamily.htm?pf=PFC2033&lang=en>
- CIHI. (2014). Health Spending - Nursing Homes. <https://secure.cihi.ca/estore/productFamily.htm?locale=en&pf=PFC2740>
- CIHR. (2012). Guide to Knowledge Translation Planning at CIHR: Integrated and End-of-Grant Approaches. <http://www.cihr-irsc.gc.ca/e/45321.html>
- CIHR. (2014). More About Knowledge Translation at CIHR. <http://www.cihr-irsc.gc.ca/e/39033.html>
- Cloutier-Fisher, D., & Joseph, A. E. (2000). Long-term care restructuring in rural Ontario: retrieving community service user and provider narratives. *Social Science & Medicine*, 50(7-8), 1037-1045. doi: [http://dx.doi.org/10.1016/S0277-9536\(99\)00353-6](http://dx.doi.org/10.1016/S0277-9536(99)00353-6)
- Coburn, A. F. (2002). Rural Long-term Care: What Do We Need to Know to Improve Policy and Programs? *The Journal of Rural Health*, 18(5), 256-269. doi: 10.1111/j.1748-0361.2002.tb00935.x
- Cole, D. (2012) Optimising nutrition for older people with dementia. *Nursing Standard*. 26(20): 41 – 48.
- Cook, C, Fa, S, Rockwood, K. (2012) A meta-ethnography of paid dementia care workers' perspectives on their jobs. *Canadian Geriatrics Journal*. 15(4): 127 – 136.
- Cohen, A., & Bulanda, J. R. (2015). Social Supports as Enabling Factors in Nursing Home Admissions: Rural, Suburban, and Urban Differences. *Journal of Applied Gerontology*. doi: 10.1177/0733464814566677
- Corner, L., Bond, John. (2004). Being at risk of dementia: Fears and anxieties of older adults. *Journal of Aging Studies*, 18, 143-155. doi: 10.1016/j.jaging.2004.01.007
- Davis, D., Evans, M., Jadad, A., Perrier, L., Rath, D., Ryan, D., Sibbald, G., Straus, S., Rappolt, S., Wowk, M., & Zwarenstein, M. (2003). The case for knowledge translation: shortening the journey from evidence to effect. *Bmj*, 327(7405), 33-35. doi: 10.1136/bmj.327.7405.33

- DiBartolo, M. C. (2006). Careful hand feeding: a reasonable alternative to PEG tube placement in individuals with dementia. *J Gerontol Nurs*, 32(5), 25-33; quiz 34-25.
- Dietitians of Canada (DC): Ontario Long Term Care Action Group. (2010). Responsibilities of the Registered Dietitian (RD) in Ontario LTC Homes. Toronto, ON: Dietitians of Canada.
- Dietitians of Canada: Ontario Long Term Care Action Group. (2013). Best Practices for Nutrition, Food Service and Dining in Long Term Care Homes. Toronto; Dietitians of Canada.
- Dominguez, L, Barbagallo, M (2017) The multidomain nature of malnutrition in older persons. *JAMDA* 18: 908 – 912
- Dominguez, L, Barbagallo, M (2017) The multidomain nature of malnutrition in older persons. *JAMDA* 18: 908 – 912
- Douglas, J. W., & Lawrence, J. C. Environmental Considerations for Improving Nutritional Status in Older Adults with Dementia: A Narrative Review. *Journal of the Academy of Nutrition and Dietetics*. doi: <http://dx.doi.org/10.1016/j.jand.2015.06.376>
- Draper, A. K. (2004). The principles and application of qualitative research. *Proceedings of the Nutrition Society*, 63(04), 641-646. doi: doi:10.1079/PNS2004397
- Ducak, K., & Keller, H. H. (2011). Menu planning in long-term care: toward resident-centred menus. *Can J Diet Pract Res*, 72(2), 83. doi: 10.3148/72.2.2011.83
- Dunne, A. (2010). Nutrition and dementia. *Nursing & Residential Care*, 12(3), 112.
- Dunne, J. L., & Dahl, W. J. (2007). A novel solution is needed to correct low nutrient intakes in elderly long-term care residents. *Nutr Rev*, 65(3), 135-138.
- Edvardsson, D., Winblad, B., & Sandman, P. O. (2008). Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *The Lancet Neurology*, 7(4), 362-367. doi: [http://dx.doi.org/10.1016/S1474-4422\(08\)70063-2](http://dx.doi.org/10.1016/S1474-4422(08)70063-2)
- Elliot, K, Scott, J, Stirling, C, Martin, A, Robinson, A. (2012) Building capacity and resilience in the dementia care workforce: a systematic review of interventions targeting worker and organizational outcomes. *International Psychogeriatrics*. 24(6): 882 – 894.
- Estabrooks, C. A., Poss, J. W., Squires, J. E., Teare, G. F., Morgan, D. G., Stewart, N., Doupe, M. B., Cummings, G. G., & Norton, P. G. (2013). A Profile of Residents in Prairie Nursing Homes. *Canadian Journal on Aging/La Revue canadienne du vieillissement*, 32(03), 223-231. doi: doi:10.1017/S0714980813000287
- Estabrooks, C. A., Squires, J. E., Carleton, H. L., Cummings, G. G., & Norton, P. G. (2015). Who is Looking After Mom and Dad? Unregulated Workers in Canadian Long-Term Care Homes. *Canadian Journal on Aging/La Revue canadienne du vieillissement*, 34(01), 47-59. doi: doi:10.1017/S0714980814000506
- Etgen, T. (2015). Cognitive Impairment and Dementia in Diet and Nutrition. In C. Martin, Preedy, V (Ed.), *Diet and Nutrition in Dementia and Cognitive Decline*. London: Elsevier.
- Feart, C., Samieri, C., & Barberger-Gateau, P. (2015). Mediterranean diet and cognitive health: an update of available knowledge. *Curr Opin Clin Nutr Metab Care*, 18(1), 51-62. doi: 10.1097/mco.0000000000000131

- Finkel, S. I. (2003). Behavioral and psychologic symptoms of dementia. *Clin Geriatr Med*, 19(4), 799-824.
- Ford, C, Foley, K, Ritchie, C, Sheppard, K, Sawyer, P, Swanson, M, Harada, C, Brown, C (2013) Creation of an Interprofessional Clinical Experience for Healthcare Professions Trainees in a Nursing Home Setting. *Medical Teacher*, 35:7, 544-548, DOI: 10.3109/0142159X.2013.787138
- Gallego, G., Dew, A., Lincoln, M., Bundy, A., Chedid, R. J., Bulkeley, K., Brentnall, J., & Veitch, C. (2015). Should I stay or should I go? Exploring the job preferences of allied health professionals working with people with disability in rural Australia. *Human Resources for Health*, 13, 53. doi: 10.1186/s12960-015-0047-x
- Gaskill, D, Black, L, Isenring, E, Hassall, S, Sanders, F, Bauer, J. (2008) Malnutrition prevalence and nutrition issues in residential aged care facilities. *Australasian Journal on Ageing*, 27(4): 189–194
- Gaskill, D, Isenring, E, Black, L, Hassall, L, Bauer, J. (2009) Maintaining nutrition in aged care residents with a train-the-trainer intervention and nutrition coordinator. *The Journal of Nutrition, Health, and Aging*. 13(10): 913 – 917.
- Gerrish, K., & Clayton, J. (2004). Promoting evidence-based practice: an organizational approach. *Journal of Nursing Management*, 12(2), 114-123. doi: 10.1111/j.1365-2834.2004.00454.x
- Gessert, C. E., Haller, I. V., Kane, R. L., & Degenholtz, H. (2006). Rural–Urban Differences in Medical Care for Nursing Home Residents with Severe Dementia at the End of Life. *Journal of the American Geriatrics Society*, 54(8), 1199-1205. doi: 10.1111/j.1532-5415.2006.00824.x
- Gibbs-Ward, A. J., & Keller, H. H. (2005). Mealtimes as Active Processes in Long-term Care Facilities. *Canadian Journal of Dietetic Practice and Research*, 66(1), 5-11.
- Gillette-Guyonnet, S., Abellan Van Kan, G., Alix, E., Andrieu, S., & et al. (2007). IANA (INTERNATIONAL ACADEMY ON NUTRITION AND AGING) EXPERT GROUP: WEIGHT LOSS AND ALZHEIMER'S DISEASE. *The Journal of Nutrition, Health & Aging*, 11(1), 38-48.
- Gitlin, L, Marx, K, Stanley, I, Hodgson, N. (2015) Translating evidence-based dementia caregiving interventions into practice: State-of-the-science and next steps. *The Gerontologist*. 55(2): 210 – 226.
- Givens, J, Kiely, D, Carey, K, Mitchell, S. (2009) Healthcare proxies of nursing home residents with advanced dementia: Decisions they confront and satisfaction with decision-making. *Journal of the American Geriatrics Society*. 57: 1149 – 1155.
- Glaser, B. (1978). *Theoretical Sensitivity*. Mill Valley, CA: Sociology Press.
- Gove, D., Sparr, S., Bernardo, A. M. C. D. S., Cosgrave, M. P., Jansen, S., Martensson, B., Pointon, B., Tudose, C., & Holmerova, I. (2010). Recommendations on end-of-life care for persons with dementia. *The Journal of Nutrition, Health & Aging*, 14(2), 136-139.
- Graham, I. D., Logan, J., Harrison, M. B., Straus, S. E., Tetroe, J., Caswell, W., & Robinson, N. (2006). Lost in knowledge translation: time for a map? *Journal of Continuing Education in the Health Professions*, 26(1), 13-24.

- Grant, M, Booth, A. (2009) A typology of reviews: An analysis of 14 review types and associated methodologies. *Health Information and Libraries Journal*. 26: 91 – 108.
- Gray, D. (2014). *Doing Research in the Real World*, 3rd ed. Los Angeles, CA: Sage.
- Greenwood, C. E., Tam, C., Chan, M., Young, K. W. H., Binns, M. A., & van Reekum, R. (2005). Behavioral Disturbances, Not Cognitive Deterioration, Are Associated With Altered Food Selection in Seniors With Alzheimer's Disease. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 60(4), 499-505. doi: 10.1093/gerona/60.4.499
- Gruber-Baldini, A. L., Zimmerman, S. I., Mortimore, E., & Magaziner, J. (2000). The validity of the minimum data set in measuring the cognitive impairment of persons admitted to nursing homes. *J Am Geriatr Soc*, 48(12), 1601-1606.
- Guyatt, G., Drummond, R., Meade, M., Cook, D. (2008). *Users' Guide to the Medical Literature: A Manual for Evidence-Based Clinical Practice*, 2nd ed. New York: McGraw Medical.
- Guyatt, G, Rennie, D, Meade, M, Cook, D eds (2015) *Users' Guides to the Medical Literature: Essentials of Evidence-based Clinical Practice* 3rd edition. New York: McGraw Hill.
- Guyatt, G., & Voelker, R. (2015). Everything you ever wanted to know about evidence-based medicine. *Jama*, 313(18), 1783-1785. doi: 10.1001/jama.2015.2845
- Hanson, L. C., Ersek, M., Lin, F. C., & Carey, T. S. (2013). Outcomes of Feeding Problems in Advanced Dementia in a Nursing Home Population. *Journal of the American Geriatrics Society*, 61(10), 1692-1697. doi: 10.1111/jgs.12448
- Harris, J. E., Gleason, P. M., Sheean, P. M., Boushey, C., Beto, J. A., & Bruemmer, B. (2009). An Introduction to Qualitative Research for Food and Nutrition Professionals. *Journal of the American Dietetic Association*, 109(1), 80-90. doi: <http://dx.doi.org/10.1016/j.jada.2008.10.018>
- Harwood, R. H. (2014). Feeding decisions in advanced dementia. *J R Coll Physicians Edinb*, 44(3), 232-237. doi: 10.4997/jrcpe.2014.310
- Hines, S, Wilson, J, McCrow, J, Abbey, J, Sacre, S. (2010) Oral liquid nutritional supplements for people with dementia in residential aged care facilities. *International Journal of Evidence-based Healthcare*. 8: 248 – 251.
- Hirdes, J. P. (2002). Long-Term Care Funding in Canada. *Journal of Aging & Social Policy*, 13(2-3), 69-81. doi: 10.1300/J031v13n02_06
- Hirdes, J. P., Mitchell, L., Maxwell, C. J., & White, N. (2011). Beyond the 'Iron Lungs of Gerontology': Using Evidence to Shape the Future of Nursing Homes in Canada. *Canadian Journal on Aging/La Revue canadienne du vieillissement*, 30(03), 371-390. doi: 10.1017/S0714980811000304
- Innes, A. (2009) *Dementia Studies: A Social Science Perspective*. Thousand Oaks, CA: Sage Publications.
- Jackson, J, Currie, K, Graham, C, Robb, Y. (2011) The effectiveness of interventions to reduce undernutrition and promote eating in older adults with dementia: A systematic review. *JBIC Library of Systematic Reviews*. 9(37): 1509 – 1550.
- Janes, N., Sidani, S., Cott, C., & Rappolt, S. (2008). Figuring it Out in the Moment: A Theory of Unregulated Care Providers' Knowledge Utilization in Dementia Care Settings. *Worldviews on Evidence-Based Nursing*, 5(1), 13-24. doi: 10.1111/j.1741-6787.2008.00114.x

- Jurkowski, C. L. (1998). A multidisciplinary approach to Alzheimer's disease: who should be members of the team? *Am J Med*, 104(4a), 13S-16S; discussion 39S-42S.
- Kang, Y., Meng, H., & Miller, N. A. (2011). Rurality and Nursing Home Quality: Evidence From the 2004 National Nursing Home Survey. *The Gerontologist*, 51(6), 761-773. doi: 10.1093/geront/gnr065
- Keane, S., Lincoln, M., & Smith, T. (2012). Retention of allied health professionals in rural New South Wales: a thematic analysis of focus group discussions. *BMC health services research*, 12, 175. doi: <http://dx.doi.org/10.1186/1472-6963-12-175>
- Keller, H. (2016) Improving food intake in persons living with dementia. *Annals of the New York Academy of Sciences*. 1367: 3 – 11.
- Keller, H, Carrier, N, Slaughter, S, Lengyel, C, Steele, C, Duzier, L, Morrison, J, Brown, K, Chaudhury, H, Yoon, M, Duncan, A, Boscart, V, Heckmen, G, Villalon, L. (2017) Prevalence and determinants of poor food intake of residents living in long-term care. *Journal of the American Medical Directors Association*. 18: 941 – 947.
- Keller, H. H., Gibbs, A. J., Boudreau, L. D., Goy, R. E., Pattillo, M. S., & Brown, H. M. (2003). Prevention of weight loss in dementia with comprehensive nutritional treatment. *Journal of the American Geriatrics Society*, 51(7), 945-952. doi: 10.1046/j.1365-2389.2003.51307.x
- Keller, H, Gibbs-Ward, A, Randall-Simpson, J, Bocock, M, Dimou, E. (2006) Meal Rounds: An essential aspect of quality nutrition services in long-term care. *Journal of the American Medical Directors Association*. 7: 40 – 45.
- Kenigsberg, P. A., Aquino, J. P., Berard, A., Gzil, F., Andrieu, S., Banerjee, S., Bremond, F., Buee, L., Cohen-Mansfield, J., Mangialasche, F., Platel, H., Salmon, E., & Robert, P. (2015). Dementia beyond 2025: Knowledge and uncertainties. *Dementia (London)*. doi: 10.1177/1471301215574785
- Khan, K., Kunz, R, Kleijnen, J, Antes, G. (2011). *Systematic Reviews to Support Evidence-based Medicine*, 2nd ed. London: Hodder Arnold.
- Kim, Y.-I. (2001). To feed or not to feed: Tube feeding in patients with advanced dementia. *Nutrition Reviews*, 59(3), 86-88.
- King, N. (2006). Using Interviews in Qualitative Research. In C. Casell, Symon, G (Ed.), *Essential Guide to Qualitative Methods in Organizational Research*. London: Sage.
- Kitwood, T., & Bredin, K. (1992). Towards a theory of dementia care: personhood and well-being. *Ageing Soc*, 12, 269-287.
- Knopp-Sihota, J. A., Niehaus, L., Squires, J. E., Norton, P. G., & Estabrooks, C. A. (2015). Factors associated with rushed and missed resident care in western Canadian nursing homes: a cross-sectional survey of health care aides. *Journal of Clinical Nursing*, n/a-n/a. doi: 10.1111/jocn.12887
- Koopmans, R. T. C. M., van der Sterren, K. J. M. A., & van der Steen, J. T. (2007). The 'natural' endpoint of dementia: death from cachexia or dehydration following palliative care? *International Journal Of Geriatric Psychiatry*, 22(4), 350-355. doi: 10.1002/gps.1680

- Kosteniuk, J. G., Morgan, D. G., O'Connell, M. E., Kirk, A., Crossley, M., Teare, G. F., Stewart, N. J., Bello-Haas, V. D., Forbes, D. A., Innes, A., & Quail, J. M. (2015). Incidence and prevalence of dementia in linked administrative health data in Saskatchewan, Canada: a retrospective cohort study. *BMC Geriatrics*, 15(1), 73-73. doi: 10.1186/s12877-015-0075-3
- Krueger, R. (1994). *Focus Groups: A Practical Guide for Applied Research*, 2nd ed. thousand Oaks: Sage.
- Kuo, S., Rhodes, R. L., Mitchell, S. L., Mor, V., & Teno, J. M. (2009). Natural history of feeding-tube use in nursing home residents with advanced dementia. *J Am Med Dir Assoc*, 10(4), 264-270. doi: 10.1016/j.jamda.2008.10.010
- Kuske, B., Hanns, S, Luck, T, Angermeyer, M, Behrens, J, Riedel-Heller, S. (2007) Nursing home staff training in dementia care: a systematic review of evaluated programs. *International Psychogeriatrics*. 19: 818- 841.
- Lann-Wolcott, H, Medvene, L, Williams, K. (2011) Measuring the person-centeredness of caregivers working with nursing home residents with dementia. *Behavior Therapy*. 42: 89 – 99.
- Leach, B., & Joseph, G. (2011). Rural Long-term Care Work, Gender, and Restructuring. *Canadian Journal on Aging/La Revue canadienne du vieillissement*, 30(02), 211-221. doi: 10.1017/S0714980811000031
- Leah, V. (2016) Supporting people with dementia to eat. *Nursing Older People*. 28(6): 33 – 39.
- Lee, J., Hui, E., Kng, C., & Auyeung, T. W. (2013). Attitudes of long-term care staff toward dementia and their related factors. *International Psychogeriatrics*, 25(01), 140-147. doi: 10.1017/S1041610212001512
- Leydon, N., & Dahl, W. (2008). Improving the nutritional status of elderly residents of long-term care homes. *J Health Serv Res Policy*, 13 Suppl 1, 25-29. doi: 10.1258/jhsrp.2007.007017
- Lezak, M., Howieson, D, Bigler, E, Tranel, D. (2012). *neuropsychological Assessment*, 5th ed. Oxford: Oxford University Press.
- Liberati, A, Altman, D, Tezloff, J, Mulrow, C, Gotzsche, P, Ioannidis, J, Clarke, M, Devereaux, P, Kleinjen, J, Moher, D. (2009) The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care and interventions: Explanation and elaboration. *PLoS Medicine*. 6(7): e1000100.
- Lilley, S., & Gaudet-LeBlanc, C. (1992). Quality of Life in Long-term Geriatric Care: The Dietitian's Role. *Journal of the Canadian Dietetic Association*, 53(3), 194 - 198.
- Lincoln, Y, Guba, E. (1985) *Naturalistic Inquiry*. Beverly Hills: Sage Publications.
- Liu, W., Cheon, J., & Thomas, S. A. (2014). Interventions on mealtime difficulties in older adults with dementia: A systematic review. *International Journal of Nursing Studies*, 51(1), 14-27. doi: <http://dx.doi.org/10.1016/j.ijnurstu.2012.12.021>
- Liu, W, Galik, E, Boltz, M, Nahm, E, Resnick, B. (2015) Optimizing eating performance for older adults with dementia living in long-term care: A systematic review. *Worldviews on Evidence-Based Nursing*. 12(4): 228 – 235.
- Lordly, D., & Taper, J. (2008). Assumptions Lead to the Devaluation of Dietitian Roles in Long-term Care Practice Environments. *Journal of Allied Health*, 37(2), 78-81.

- Lou, M. F., Dai, Y. T., Huang, G. S., & Yu, P. J. (2007). Nutritional status and health outcomes for older people with dementia living in institutions. *J Adv Nurs*, 60(5), 470-477. doi: 10.1111/j.1365-2648.2007.04442.x
- Lourida, I., Soni, M., Thompson-Coon, J., Purandare, N., Lang, I. A., Ukoumunne, O. C., & Llewellyn, D. J. (2013). Mediterranean diet, cognitive function, and dementia: a systematic review. *Epidemiology*, 24(4), 479-489. doi: 10.1097/EDE.0b013e3182944410
- Low, L., Fletcher, J., Goodenough, B., Jeon, Y., Etherton-Beer, C., MacAndrew, M., Beattie, E. (2015) A systematic review of interventions to change staff care practices in order to improve resident outcomes in nursing homes. *PLoS One* 10(11): 1 – 60.
- Lowndes, R., Armstorng, P., Daly, T. (2015) The meaning of dining: The social organization of food in long-term care. *Food Studies*. 4: 19 – 34.
- Manahan, C. M., Hardy, C. L., & MacLeod, M. L. P. (2009). Personal characteristics and experiences of long-term allied health professionals in rural and northern British Columbia. *Rural And Remote Health*, 9(4), 1238-1238.
- Manthorpe, J., Watson, R. (2003) Poorly served? Eating and dementia. *Journal of Advanced Nursing*. 41(2): 162 – 169.
- McConnell, E. S., Lekan, D., Hebert, C., & Leatherwood, L. (2007). Academic-practice partnerships to promote evidence-based practice in long-term care: Oral hygiene care practices as an exemplar. *Nursing Outlook*, 55(2), 95-105. doi: <http://dx.doi.org/10.1016/j.outlook.2006.12.003>
- McKeith, I., & Cummings, J. (2005). Behavioural changes and psychological symptoms in dementia disorders. *The Lancet Neurology*, 4(11), 735-742. doi: [http://dx.doi.org/10.1016/S1474-4422\(05\)70219-2](http://dx.doi.org/10.1016/S1474-4422(05)70219-2)
- McKhann, G. M., Knopman, D. S., Chertkow, H., Hyman, B. T., Jack Jr, C. R., Kawas, C. H., Klunk, W. E., Koroshetz, W. J., Manly, J. J., Mayeux, R., Mohs, R. C., Morris, J. C., Rossor, M. N., Scheltens, P., Carrillo, M. C., Thies, B., Weintraub, S., & Phelps, C. H. (2011). The diagnosis of dementia due to Alzheimer's disease: Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's & Dementia*, 7(3), 263-269. doi: <http://dx.doi.org/10.1016/j.jalz.2011.03.005>
- McLean, A. (2007). *The Person in Dementia: A Study of Nursing Home Care in the US*. Peterborough, ON: Broadview Press.
- Meijers, J. M., Schols, J. M., & Halfens, R. J. (2014). Malnutrition in care home residents with dementia. *J Nutr Health Aging*, 18(6), 595-600. doi: 10.1007/s12603-014-0006-6
- Milte, R., Shulvera, W., Killington, M., Bradley, C., Miller, M., Crotty, M (2017) Struggling to maintain individuality: Describing the experience of food in nursing homes for people with dementia. *Archives of Gerontology and Geriatrics* 72: 52–58
- Mitchell, S. L., Teno, J. M., Kiely, D. K., Shaffer, M. L., Jones, R. N., Prigerson, H. G., Volicer, L., Givens, J. L., & Hamel, M. B. (2009). The Clinical Course of Advanced Dementia. *New England Journal of Medicine*, 361(16), 1529-1538. doi: doi:10.1056/NEJMoa0902234
- Morgan, D. (2004). Focus Groups. In S. Nagy Hesse-Biber, Leavy, P (Ed.), *Approaches to Qualitative Research: A Reader on Theory and Practice*. New York: Oxford Univerrsty Press.

- Morgan, D. G., Cammer, A., Stewart, N. J., Crossley, M., D'Arcy, C., Forbes, D. A., & Karunanayake, C. (2012). Nursing aide reports of combative behavior by residents with dementia: results from a detailed prospective incident diary. *J Am Med Dir Assoc*, 13(3), 220-227. doi: 10.1016/j.jamda.2011.07.003
- Morley, J. E. (2014). Cognition and nutrition. *Curr Opin Clin Nutr Metab Care*, 17(1), 1-4. doi: 10.1097/mco.0000000000000005
- Morley, J. E., Caplan, G., Cesari, M., Dong, B., Flaherty, J. H., Grossberg, G. T., Holmerova, I., Katz, P. R., Koopmans, R., Little, M. O., Martin, F., Orrell, M., Ouslander, J., Rantz, M., Resnick, B., Rolland, Y., Tolson, D., Woo, J., & Vellas, B. (2014). International Survey of Nursing Home Research Priorities. *Journal of the American Medical Directors Association*, 15(5), 309-312. doi: <http://dx.doi.org/10.1016/j.jamda.2014.03.003>
- Morris, J., & Volicer, L. (2001). Nutritional Management of Individuals with Alzheimer's Disease and Other Progressive Dementias. *Nutrition in Clinical Care*, 4(3), 148-155. doi: 10.1046/j.1523-5408.2001.00136.x
- Morris, M. C., Tangney, C. C., Wang, Y., Sacks, F. M., Barnes, L. L., Bennett, D. A., & Aggarwal, N. T. (2015). MIND diet slows cognitive decline with aging. *Alzheimers Dement*. doi: 10.1016/j.jalz.2015.04.011
- Morris, M. C., Tangney, C. C., Wang, Y., Sacks, F. M., Bennett, D. A., & Aggarwal, N. T. (2015). MIND diet associated with reduced incidence of Alzheimer's disease. *Alzheimers Dement*. doi: 10.1016/j.jalz.2014.11.009
- Morse, J. (2012). *Qualitative Health research: Creating a New Discipline*. Walnut Creek, CA: Left Coast Press.
- Murphy, J, Holmes, J, Brooks, C. (2017) Nutrition and dementia care: developing an evidence-based model for nutritional care in nursing homes. *BMC Geriatrics*. 17:55. DOI 10.1186/s12877-017-0443-2
- Myonghwa, P. (2015) Implementing evidence into practice for best dementia care. *Journal of Korean Academy of Nursing*. 45(4): 495 – 500.
- Nay, R. (2003). Evidence-based practice: Does it benefit older people and gerontic nursing? *Geriatric Nursing*, 24(6), 338-342. doi: <http://dx.doi.org/10.1016/j.gerinurse.2003.10.001>
- Nell, D, Neville, S, Bellow, R, O'Leary, C, Beck, K (2016) Factors affecting optimal nutrition and hydration for people living in specialised dementia care units: A qualitative study of staff caregivers' perceptions. *Australasian Journal on Ageing*, 35(4): E1–E6
- Norberg, A., Backstrom, A., Athlin, E., & Norberg, B. (1988). Food refusal amongst nursing home patients as conceptualized by nurses' aids and enrolled nurses: an interview study. *J Adv Nurs*, 13(4), 478-483.
- Norton, S., Matthews, F. E., Barnes, D. E., Yaffe, K., & Brayne, C. (2014). Potential for primary prevention of Alzheimer's disease: an analysis of population-based data. *Lancet Neurol*, 13(8), 788-794. doi: 10.1016/s1474-4422(14)70136-x
- O'Brien, J. (2003). Behavioral symptoms in vascular cognitive impairment and vascular dementia. *Int Psychogeriatr*, 15 Suppl 1, 133-138. doi: 10.1017/s1041610203009098

- O'Brien, J. (2003). Behavioral Symptoms in Vascular Cognitive Impairment and Vascular Dementia. *International Psychogeriatrics*, 15(SupplementS1), 133-138. doi: doi:10.1017/S1041610203009098
- OECD. (2005). Long-term Care for Older People. http://www.oecd-ilibrary.org/social-issues-migration-health/long-term-care-for-older-people_9789264015852-en
- OECD. (2013). Public Spending on Health and Long-term Care: A New Set of Projections. <http://www.oecd.org/els/health-systems/long-term-care.htm>
- Ontario Ministry of Health. (2010). O. Reg 79/10 General, Long-term Care Homes Act, 2007, S.O. 2007, c.8.
- Parker, M., & Power, D. (2013). Management of swallowing difficulties in people with advanced dementia. *Nurs Older People*, 25(2), 26-31. doi: 10.7748/ncyp2013.07.25.6.26.e195
- Pasman, H., Onwuteaka-Philipsen, B., van der Wal, G., and Ribbe, M. (2003) Feeding nursing home patients with severe dementia: a qualitative study. *Journal of Advanced Nursing*, 42(3), 304–311.
- Pearson, A., Fitzgerald, M., & Nay, R. (2003). Mealtimes in nursing homes. The role of nursing staff. *J Gerontol Nurs*, 29(6), 40-47.
- Pelletier, C. A. (2005). Feeding beliefs of certified nurse assistants in the nursing home: a factor influencing practice. *J Gerontol Nurs*, 31(7), 5-10.
- Persson, T., & Wästerfors, D. (2009). “Such Trivial Matters:” How staff account for restrictions of residents' influence in nursing homes. *Journal of Aging Studies*, 23(1), 1-11. doi: <http://dx.doi.org/10.1016/j.jaging.2007.09.005>
- Petersson, S., & Philippou, E. (2016). The effects of Mediterranean Diet on cognitive function and dementia: Systematic review of evidence. *Clinical Nutrition ESPEN*. 13, e67
- Phillips, C. D., Holan, S., Sherman, M., Williams, M. L., & Hawes, C. (2004). Rurality and Nursing Home Quality: Results from a National Sample of Nursing Home Admissions. *American Journal of Public Health*, 94(10), 1717-1722.
- Piguet, O., Petersén, Å., Yin Ka Lam, B., Gabery, S., Murphy, K., Hodges, J. R., & Halliday, G. M. (2011). Eating and hypothalamus changes in behavioral-variant frontotemporal dementia. *Annals of Neurology*, 69(2), 312-319. doi: 10.1002/ana.22244
- Pilnick, A., & Swift, J. A. (2011). Qualitative research in nutrition and dietetics: assessing quality. *Journal of Human Nutrition & Dietetics*, 24(3), 209-214.
- Pivi, G, Bertolucci, P, Schultz, R. (2012) Nutrition in severe dementia. *Current Gerontology and Geriatrics Research*. 1 – 7.
- Prince, M., Albanese, E., Guerchet, M., & Prina, M. (2013). Policy Brief: The Global Impact of Dementia 2013 - 2050: 1.
- Prince, M., Albanese, E., Guerchet, M., Prina, M. (2014) Nutrition and Dementia: A Review of Available Research. *Alzheimer's Disease International*, London.
- Quinn Patton, M. (2002). *Qualitative Research and Evaluation Methods*, 3rd ed. Thousand Oaks: Sage.

- Rabiee, F. (2004). Focus-group interview and data analysis. *Proceedings of the Nutrition Society*, 63(4), 655-660.
- Rahman, A, Simmons, S, Applebaum, R, Lindabury, K, Schnelle, J. (2012) The coach is in: Improving nutritional care in nursing homes. *The Gerontologist*. 52(4): 571 – 580.
- Reimer, H. D., & Keller, H. H. (2009). Mealtimes in nursing homes: striving for person-centered care. *Journal of Nutrition for the Elderly*, 28(4), 327-347. doi: 10.1080/01639360903417066
- Ribeiro Salomon, A. L., & Carvalho Garbi Novaes, M. R. (2015). Outcomes of enteral nutrition for patients with advanced dementia: a systematic review. *J Nutr Health Aging*, 19(2), 169-177. doi: 10.1007/s12603-014-0517-1
- Roberts, L, Cryst, S, Robinson, G, Elliott, C, Moore, L, Rybicki, M, Carlson, M. (2011) American Dietetic Association: Standards of practice and standards of professional performance for registered dietitians (competent, proficient, and expert) in extended care settings. *Journal of the American Dietetic Association*. 111(4): 617 – 624.e27
- Rolland, Y., & de Souto Barreto, P. (2013). Research Can Improve Care in the Nursing Home. *Journal of the American Medical Directors Association*, 14(4), 233-235. doi: <http://dx.doi.org/10.1016/j.jamda.2013.01.019>
- Roller, R, Morgner, A, Eglseer, D, Wirnsberger, G. (2016) Nursing home professionals opinions on determinants of malnutrition: A qualitative study. *The Journal of Nursing Home Research Services*. 2: 1 – 7.
- Sackett, D. L., Rosenberg, W. M. C., Gray, J. A. M., Haynes, R. B., & Richardson, W. S. (1996). *Evidence based medicine: what it is and what it isn't* (Vol. 312).
- Sackett, D, Strauss, S, Richardson, W, Rosenberg, W, Hayes, R. (2000). *Evidence-based Medicine: How to Practice and teach EBM* 2nd ed. New York: Churchill Livingstone.
- Salva, A., Coll-Planas, L., Bruce, S., De Groot, L., Andrieu, S., Abellan, G., Vellas, B., Andrieu, S., Bartorelli, L., Berner, Y. N., Bruce, S., Corman, B., Domingo, A., Egger, T. P., de Groot, L., Guigoz, Y., Imedio, A., Planas, M., Porras, C., Rovira, J. C., Salva, A., Serra, J. A., & Vellas, B. (2009). Nutritional assessment of residents in long-term care facilities (LTCFs): recommendations of the task force on nutrition and ageing of the IAGG European region and the IANA. *J Nutr Health Aging*, 13(6), 475-483.
- Santana, M, Manalili, K, Jolley, R, Zelinsky, S, Quan, H, Lu, M. (2017) How to practice person-centered care: A conceptual framework. *Health Expectations*. 21: 429 – 440.
- Saskatchewan Health. (2013). Program Guidelines for Special Care Homes. <http://www.saskatchewan.ca/live/health-and-healthy-living/manage-your-health-needs/care-at-home-and-outside-the-hospital/special-care-homes>
- Shah, R. (2013). The Role of Nutrition and Diet in Alzheimer Disease: A Systematic Review. *Journal of the American Medical Directors Association*, 14(6), 398-402. doi: <http://dx.doi.org/10.1016/j.jamda.2013.01.014>
- Shenton, A. (2004) Strategies for ensuring trustworthiness in qualitative research. *Education for Information*. 22: 63 – 75.

- Shinagawa, S., Adachi, H., Toyota, Y., Mori, T., Matsumoto, I., Fukuhara, R., & Ikeda, M. (2009). Characteristics of eating and swallowing problems in patients who have dementia with Lewy bodies. *International Psychogeriatrics*, 21(03), 520-525. doi: 10.1017/S1041610209008631
- Sidenvall, B. (1999). Meal procedures in institutions for elderly people: a theoretical interpretation. *J Adv Nurs*, 30(2), 319-328.
- Simmon, S, Levy-Storms, L. (2006) The effect of staff care practices on nursing home residents' preference: Implications for individualized care. *Journal of Nutrition, Aging, and Health*. 10(3): 216 – 221.
- Sindi, S., Mangialasche, F., & Kivipelto, M. (2015). Advances in the prevention of Alzheimer's Disease. *F1000Prime Rep*, 7, 50. doi: 10.12703/p7-50
- Skinner, M. W., & Rosenberg, M. W. (2006). Managing competition in the countryside: Non-profit and for-profit perceptions of long-term care in rural Ontario. *Social Science & Medicine*, 63(11), 2864-2876. doi: <http://dx.doi.org/10.1016/j.socscimed.2006.07.028>
- Smele, S., Seley, M. (2013). Balancing the Tensions in Resident-Centered Care. In P. Armstrong (Ed.), *Troubling Care: Critical Perspectives on Research and Practice*. Toronto, ON: Canadian Scholars' Press Inc.
- Smith, A. (2011). A brief overview of dietetic issues for people with late stage dementia. *British Journal of Community Nursing*, 16, S6-S12.
- Smith, K. L., & Greenwood, C. E. (2008). Weight Loss and Nutritional Considerations in Alzheimer Disease. *Journal of Nutrition For the Elderly*, 27(3-4), 381-403. doi: 10.1080/01639360802265939
- Specht, J. K. (2013). Evidence based practice in long term care settings. *J Korean Acad Nurs*, 43(2), 145-153. doi: 10.4040/jkan.2013.43.2.145
- Statistics Canada. (2011a). 2011 Census of Canadian Population - Population, urban and rural, by province and territory (Canada). <http://www.statcan.gc.ca/tables-tableaux/sum-som/101/cst01/demo62a-eng.htm>
- Statistics Canada. (2011b). 2011 Census of Canadian Population - Population, urban and rural, by province and territory (Saskatchewan). <http://www.statcan.gc.ca/tables-tableaux/sum-som/101/cst01/demo62i-eng.htm>
- Statistics Canada. (2011c). 2011 Census of the Canadian Population - Canada goes Urban. <http://www.statcan.gc.ca/pub/11-630-x/11-630-x2015004-eng.htm>
- Statistics Canada. (2011d). Residential Care Facilities 2009/2010. <http://www.statcan.gc.ca/pub/83-237-x/83-237-x2012001-eng.htm>
- Sultzer, D. L., Levin, H. S., Mahler, M. E., High, W. M., & Cummings, J. L. (1993a). A comparison of psychiatric symptoms in vascular dementia and Alzheimer's disease. *Am J Psychiatry*, 150(12), 1806-1812.
- Sultzer, D. L., Levin, H. S., Mahler, M. E., High, W. M., & Cummings, J. L. (1993b). A comparison of psychiatric symptoms in vascular dementia and Alzheimer's disease. *The American journal of psychiatry*, 150(12), 1806-1812.

- Suominen, M., Muurinen, S., Routasalo, P., Soini, H., Suur-Uski, I., Peiponen, A., Finne-Soveri, H., & Pitkala, K. H. (2005). Malnutrition and associated factors among aged residents in all nursing homes in Helsinki. *Eur J Clin Nutr*, 59(4), 578-583. doi: 10.1038/sj.ejcn.1602111
- Suominen, M. H., Kivisto, S. M., & Pitkala, K. H. (2007). The effects of nutrition education on professionals' practice and on the nutrition of aged residents in dementia wards. *Eur J Clin Nutr*, 61(10), 1226-1232.
- Tamura, B. K., Bell, C. L., Masaki, K. H., & Amella, E. J. (2013). Factors Associated With Weight Loss, Low BMI, and Malnutrition Among Nursing Home Patients: A Systematic Review of the Literature. *Journal of the American Medical Directors Association*, 14(9), 649-655. doi: <http://dx.doi.org/10.1016/j.jamda.2013.02.022>
- Tangney, C. C., Li, H., Wang, Y., Barnes, L., Schneider, J. A., Bennett, D. A., & Morris, M. C. (2014). Relation of DASH- and Mediterranean-like dietary patterns to cognitive decline in older persons. *Neurology*, 83(16), 1410-1416. doi: 10.1212/wnl.0000000000000884
- Terada, S., Oshima, E., Yokota, O., Ikeda, C., Nagao, S., Takeda, N., Sasaki, K., & Uchitomi, Y. (2013). Person-centered care and quality of life of patients with dementia in long-term care facilities. *Psychiatry Research*, 205(1-2), 103-108. doi: <http://dx.doi.org/10.1016/j.psychres.2012.08.028>
- Thoma, A., & Eaves, F. F. (2015). A Brief History of Evidence-Based Medicine (EBM) and the Contributions of Dr David Sackett.
- Tolson, D., Rolland, Y., Andrieu, S., Aquino, J.-P., Beard, J., Benetos, A., Berrut, G., Coll-Planas, L., Dong, B., Forette, F., Franco, A., Franzoni, S., Salvà, A., Swagerty, D., Trabucchi, M., Vellas, B., Volicer, L., & Morley, J. E. (2011). International Association of Gerontology and Geriatrics: A Global Agenda for Clinical Research and Quality of Care in Nursing Homes. *Journal of the American Medical Directors Association*, 12(3), 184-189. doi: <http://dx.doi.org/10.1016/j.jamda.2010.12.013>
- Ullrich, S., McCutcheon, H., & Parker, B. (2011). Reclaiming time for nursing practice in nutritional care: outcomes of implementing Protected Mealtimes in a residential aged care setting. *J Clin Nurs*, 20(9-10), 1339-1348. doi: 10.1111/j.1365-2702.2010.03598.x
- US Department of Health. (2006). DASH Eating Plan. <http://www.pennutrition.com.cyber.usask.ca/KnowledgePathway.aspx?kpid=674&trid=813&trcatid=32>
- Volicer, L., Frijters, D. H., & van der Steen, J. T. (2013). Apathy and weight loss in nursing home residents: longitudinal study. *J Am Med Dir Assoc*, 14(6), 417-420. doi: 10.1016/j.jamda.2012.12.004
- Volicer, L., Seltzer, B., Rheau, Y., Karner, J., Glennon, M., Riley, M. E., & Crino, P. (1989). Eating Difficulties in Patients With Probable Dementia of the Alzheimer Type. *Journal of Geriatric Psychiatry and Neurology*, 2(4), 188-195. doi: 10.1177/089198878900200404
- Volkert, D., Chourdakis, M., Faxen-Irving, G., Fruhwald, T., Landia, F., Suominen, M., Vandewoude, M., Wirth, R., Schneider, S. (2015). ESPEN guidelines on nutrition in dementia. *Clinical Nutrition*. 34(6): 1052 – 1073.

- Vucea, V., Keller, H. H., & Ducak, K. (2014). Interventions for improving mealtime experiences in long-term care. *J Nutr Gerontol Geriatr*, 33(4), 249-324. doi: 10.1080/21551197.2014.960339
- Wassink, H., & Chapman, G. (2010). Vancouver Dietitians' Perspectives on Their Roles in Long-term Care. *Canadian Journal of Dietetic Practice and Research*, 71(1), e12-17.
- Watkins, R, Goodwin, V, Abbott, R, Hall, A, Tarrant, M. (2017) Exploring residents' experiences of mealtimes in care homes: A qualitative interview study. *BMC Geriatrics*. 17(141): 1 – 9.
- Watson, R, Green, S. (2006) Feeding and dementia: A systematic literature review. *Journal of Advanced Nursing*. 86 – 93.
- Weijenberg, R. A., Scherder, E. J., & Lobbezoo, F. (2011). Mastication for the mind--the relationship between mastication and cognition in ageing and dementia. *Neurosci Biobehav Rev*, 35(3), 483-497. doi: 10.1016/j.neubiorev.2010.06.002
- Whear, R, Abbott, R, Thompson-Coon, J, Bethel, A, Rogers, M, Hemsley, A, Stahl-Timmins, W, Stein, K. (2014) Effectiveness of mealtime interventions on behavior symptoms of people with dementia living in care homes: A systematic review. *Journal of the American Medical Directors Association*. 15: 185 – 193.
- White, H. (2005) Nutrition in advanced dementia. *North Carolina Medical Journal*. 66(4): 307 – 312.
- Whitmer, R. A., Gunderson, E. P., Barrett-Connor, E., Quesenberry, C. P., Jr., & Yaffe, K. (2005). Obesity in middle age and future risk of dementia: a 27 year longitudinal population based study. *Bmj*, 330(7504), 1360. doi: 10.1136/bmj.38446.466238.E0
- Whitmer, R. A., Gustafson, D. R., Barrett-Connor, E., Haan, M. N., Gunderson, E. P., & Yaffe, K. (2008). Central obesity and increased risk of dementia more than three decades later. *Neurology*, 71(14), 1057-1064. doi: 10.1212/01.wnl.0000306313.89165.ef
- WHO. (2003). Key Policy Issues in Long-term Care.
http://www.who.int/chp/knowledge/publications/policy_issues_ltc/en/
- WHO. (2012). Dementia: A Public Health Priority.
http://www.who.int/mental_health/publications/dementia_report_2012/en/
- Woo, J, Chi, I, Hui, E, Chan, F, Sham, A (2005) Low staffing level is associated with malnutrition in long-term residential care homes. *European Journal of Clinical Nutrition* 59: 474 – 479
- Wong, S, Gilmour, H, Ramage-Morin, P. (2016) Alzheimer's Disease and other dementias in Canada. *Statistics Canada Health Reports*. 27(5): 11 – 16.
- Woolley, J. D., Khan, B. K., Natesan, A., Karydas, A., Dallman, M., Havel, P., Miller, B. L., & Rankin, K. P. (2014). Satiety-related hormonal dysregulation in behavioral variant frontotemporal dementia. *Neurology*, 82(6), 512-520. doi: 10.1212/wnl.0000000000000106
- Zoellner, J., Van Horn, L., Gleason, P. M., & Boushey, C. J. (2015). What Is Translational Research? Concepts and Applications in Nutrition and Dietetics. *Journal of the Academy of Nutrition and Dietetics*, 115(7), 1057-1071. doi: <http://dx.doi.org/10.1016/j.jand.2015.03.010>

Appendix 1: Consent form, Care Aide study



Nutrition care best practices for residents with dementia in long-term care homes: Perspectives of care aides

Researcher: Allison Cammer, University of Saskatchewan (306-966-6075)

Supervisors: Dr. Debra Morgan, CCHSA, College of Medicine, University of Saskatchewan (306-966-7905), Dr. Susan Whiting, College of Pharmacy and Nutrition, University of Saskatchewan (306-966-5837)

This information sheet is part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully.

What is the research study about?

The purpose of this study is to expand our understanding of nutrition care for residents who have dementia living in long-term care homes

What do we hope to learn?

- We hope to learn about challenges experienced by care aides in providing nutrition care for residents with dementia
- We hope to learn strategies care aides use to successfully provide nutrition care for residents with dementia

What role can you play in the study?

- Participate in a focus group discussion sharing your experience as a care aide.
- With your consent, the interview will be audio recorded, and the recording will be transcribed.
- You may refuse to answer any questions, leave the focus group discussion at anytime, or withdraw from the study at any time.
- You do not have to answer any questions or discuss any subject in the discussion if you do not want to.

Who is eligible to participate in this study?

- Care aides of the LTC home are eligible to participate in this study.

Do you have to take part in this study?

- No one has to take part in the study but we would welcome any care aide who wants to participate.
- Your agreement to complete and return the consent form will be interpreted as an indication of your agreement to participate.

- You have the right to refuse to answer any questions, or withdraw from the study at any time.

What are the benefits of participating in the study?

- While you may not benefit directly from the study, the information gained may assist health care providers to better understand practical strategies of nutrition care for LTC residents with dementia can be improved. Having an understanding of this will help us to identify ways to improve quality care.

What are the risks of participating in this study?

- There are no anticipated risks for you as a participant, and taking part in this study or withdrawing will in no way affect your work or treatment at this LTC home.

Will you be paid for participating in the study, or do you have to pay for anything?

- You will not receive payment and you will not be asked to pay for anything.

Will your information be kept private?

- Yes. Data from recorded discussion will be handled in a way that protects your privacy. No information that identifies you will be disclosed. You will not be identified in any report or presentation which may arise from the study.
- Data may be used for other research studies in the future. If this is done, ethical review will first be obtained.
- All information will be held confidential except when professional codes of ethics and/or legislation require reporting.
- All of the data will be kept in a safe place accessible only to the research team.
- Your signed consent forms will be kept separately from your information sheets and will not be connected.
- The data will be kept in a secure location after the study is complete for a minimum of 5 years.
- As a participant in the focus group, we ask you to keep the information shared in the focus group confidential. While the investigators will do everything possible to ensure that the information you provide is kept confidential, please understand that they cannot guarantee that other participants in the group will do the same.

Agreement to participate

- If you agree to participate in this focus group you will asked to sign this consent form.
- In no way does this waive your legal rights nor release the researchers, or involved institutions from their legal and professional responsibilities.
- You are free to withdraw from the study at any time.

What time commitment will be involved?

- The focus group discussion will take about 30 minutes.

Who can you contact if you have questions about the study?

- If you have any questions about the study you can contact:
 - Allison Cammer (306-966-6075), allison.cammer@usask.ca

- This study has been approved by the Research Ethics Board at the University of Saskatchewan. If you have any questions about your rights as a participant please contact the Research Ethics Office at the University of Saskatchewan (306-966-2084)

Your signature below indicates that you have read and understand the description provided, have had an opportunity to ask questions, and questions have been answered.

I consent to participate in this research project. A copy of this consent form has been given to me for my records:

Name of Participant: _____ Signature: _____
Date: _____

Researcher Signature: _____ Date: _____

Appendix 2: Consent form, Registered Dietitian study



Nutrition care best practices for residents with dementia in long-term care homes: Perspectives of Registered Dietitians

Researcher: Allison Cammer, University of Saskatchewan (306-966-6075)

Supervisors: Dr. Debra Morgan, CCHSA, College of Medicine, University of Saskatchewan (306-966-7905), Dr. Susan Whiting, College of Pharmacy and Nutrition, University of Saskatchewan (306-966-5837)

This information sheet is part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully.

What is the research study about?

The purpose of this study is to expand our understanding of nutrition care for residents who have dementia living in long-term care homes (LTC).

What do we hope to learn?

- We hope to learn about challenges experienced by registered dietitians (RDs) in providing nutrition care for residents with dementia.
- We hope to learn strategies RDs use to successfully provide nutrition care for residents with dementia.

What role can you play in the study?

- Participate in an interview sharing your experience as a RD working in LTC.
- With your consent, the interview will be audio recorded, and the recording will be transcribed.
- You may refuse to answer any questions, stop the interview at anytime, or withdraw from the study at any time.
- You do not have to answer any questions or discuss any subject in the interview if you do not want to.

Who is eligible to participate in this study?

- RDs who provide service to LTC are eligible to participate in this study.

Do you have to take part in this study?

- No one has to take part in the study but we would welcome any RD who wants to participate.
- Your agreement to complete and return the consent form will be interpreted as an indication of your agreement to participate.

- You have the right to refuse to answer any questions, or withdraw from the study at any time.

What are the benefits of participating in the study?

- While you may not benefit directly from the study, the information gained may assist health care providers to better understand practical strategies of nutrition care for LTC residents with dementia can be improved. Having an understanding of this will help us to identify ways to improve quality care.

What are the risks of participating in this study?

- There are no anticipated risks for you as a participant, and taking part in this study or withdrawing will in no way affect your work.

Will you be paid for participating in the study, or do you have to pay for anything?

- You will not receive payment and you will not be asked to pay for anything. You will receive a small honorarium gift as a thank you for participating.

Will your information be kept private?

- Yes. Data from recorded discussion will be handled in a way that protects your privacy. No information that identifies you will be disclosed. You will not be identified in any report or presentation which may arise from the study.
- Data may be used for other research studies in the future. If this is done, ethical review will first be obtained.
- All information will be held confidential except when professional codes of ethics and/or legislation require reporting.
- All of the data will be kept in a safe place accessible only to the research team.
- Your signed consent forms will be kept separately from any identifying information or data and will not be connected.
- The data will be kept in a secure location after the study is complete for a minimum of 5 years.

Agreement to participate

- If you agree to participate in an interview you will asked to sign this consent form.
- In no way does this waive your legal rights nor release the researchers, or involved institutions from their legal and professional responsibilities.
- You are free to withdraw from the study at any time.

What time commitment will be involved?

- The interview will take approximately one hour.

Who can you contact if you have questions about the study?

- If you have any questions about the study you can contact:
 - Allison Cammer (306-966-6075), allison.cammer@usask.ca
- This study has been approved by the Research Ethics Board at the University of Saskatchewan. If you have any questions about your rights as a participant please contact the Research Ethics Office at the University of Saskatchewan (306-966-2084)

Your signature below indicates that you have read and understand the description provided, have had an opportunity to ask questions, and questions have been answered.

I consent to participate in this research project. A copy of this consent form has been given to me for my records:

Name of Participant: _____ Signature: _____
Date: _____

Researcher Signature: _____ Date: _____

Appendix 3: Umbrella Review Sample Search Strategy

Appendix 3: Umbrella Review Sample Search Strategy (MESH terms and keywords)

Database: Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) <1946 to Present>

Search Strategy:

-
- 1 exp Dementia/ (153787)
 - 2 (alzheimer* or dement*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (214516)
 - 3 1 or 2 (232035)
 - 4 exp "diet, food, and nutrition"/ (1641626)
 - 5 exp Nutrition Therapy/ (99251)
 - 6 feeding methods/ or enteral nutrition/ (20747)
 - 7 (Nutrition* or eat* or meal* or diet* or feed* or dine? or dining).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (1360403)
 - 8 4 or 5 or 6 or 7 (2342953)
 - 9 3 and 8 (14330)
 - 10 limit 9 to (english language and humans and yr="2000 - 2017") (8088)
 - 11 review?.mp. (3091482)
 - 12 10 and 11 (2725)
 - 13 Long-Term Care/ (25329)
 - 14 exp Nursing Homes/ (37209)
 - 15 (home? for the aged or old age home? or residential home? or nursing home? or special care home? or personal care home? or group home? or long-term care or longterm care or residential

facilit*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (83275)

16 13 or 14 or 15 (86180)

17 9 and 10 and 11 and 16
